

---

**An Examination of Factors Influencing the Experience of Stress in  
Mothers of Children with Learning Disabilities**

---

**SHONA R.P. QUIN**

**DOCTORATE IN CLINICAL PSYCHOLOGY**

**UNIVERSITY OF EDINBURGH**

**2003**





### Acknowledgements

I would like to acknowledge the advice and support of the following people in the preparation of this thesis:

- George Murray, for his clinical supervision of this thesis and for his continual support and supervision throughout my training
- Suzanne O'Rourke, for her academic supervision of this thesis and support throughout my final year of training
- Antony Quin, for his undivided support and encouragement throughout my training and always
- Helen and Fraser Patrick, for their ongoing support
- Kirsten Nicolson for keeping me sane throughout the writing of this thesis and for being the best sister in the world
- Finally, thanks to all mothers who participated in this study, for their interest and enthusiasm, especially those mothers of children with learning disabilities, whose circumstances motivated me to conduct this study.

## **Contents**

## **Page Number**

### **ABSTRACT**

|            |  |           |
|------------|--|-----------|
| <b>1</b>   | <b><u>INTRODUCTION</u></b> .....   | <b>1</b>  |
| <b>1.1</b> | <b>Setting The Scene</b> .....   | <b>2</b>  |
| 1.1.1      | <i>What Is A Learning Disability?</i> .....                              | 2         |
| 1.1.2      | <i>Prevalence of Children with Learning Disabilities In The UK</i> ..... | 2         |
| 1.1.3      | <i>Epidemiology of learning Disabilities</i> .....                       | 3         |
| 1.1.4      | <i>Political Background</i> .....  | 3         |
| 1.1.5      | <i>Service Issues</i> .....  | 4         |
| <b>1.2</b> | <b>The Child with Learning Disabilities and Their Environment</b> .....  | <b>5</b>  |
| 1.2.1      | <i>The Child with Learning Disabilities</i> .....                        | 5         |
| 1.2.2      | <i>The Impact of the Environment</i> .....                               | 5         |
| <b>1.3</b> | <b>The Relationship Between the Child and Their Mother</b> .....         | <b>8</b>  |
| 1.3.1      | <i>The Inter-relationship Between the Mother And her Child</i> .....     | 8         |
| 1.3.2      | <i>The Mother / infant Bond</i> .....                                    | 8         |
| <b>1.4</b> | <b>The Impact of the Child Upon Their Environment</b> .....              | <b>11</b> |
| 1.4.1      | <i>The Developmental Perspective</i> .....                               | 11        |
| 1.4.2      | <i>The Sociological Perspective</i> .....                                | 12        |
| 1.4.3      | <i>The Psychological Perspective</i> .....                               | 13        |
| <b>1.5</b> | <b>Maternal Stress and the Child with Learning Disabilities</b> .....    | <b>14</b> |
| 1.5.1      | <i>Approaches to the Study of Stress</i> .....                           | 14        |
| 1.5.2      | <i>The Process Model of Stress and Coping</i> .....                      | 15        |
| 1.5.3      | <i>The Mothers Experience of Stress</i> .....                            | 15        |
| <b>1.6</b> | <b>Factors Influencing the Mother's Experience of Stress</b> .....       | <b>17</b> |
| 1.6.1      | <i>Characteristics of the Child</i> .....                                | 17        |
| 1.6.2      | <i>Characteristics of the Mother</i> .....                               | 26        |
| 1.6.3      | <i>Characteristics of the Environment</i> .....                          | 34        |
| <b>1.7</b> | <b>Introduction to Research</b> .....                                    | <b>44</b> |
| <b>1.8</b> | <b>Aims of This Study</b> .....  | <b>45</b> |



|       |   |    |
|-------|---|----|
| 2.    | <b><u>HYPOTHESES</u></b> .....                            | 46 |
| 3.    | <b><u>METHOD</u></b> .....                                | 48 |
| 3.1   | <b>Design</b> .....                                       | 48 |
| 3.2   | <b>Procedure</b> .....                                    | 49 |
| 3.3   | <b>Participants</b> .....                                 | 51 |
| 3.4   | <b>Measures</b> .....                                     | 56 |
| 3.4.1 | <i>Demographic Instrument</i> .....                       | 56 |
| 3.4.2 | <i>Challenging Behaviour Questionnaire</i> .....          | 57 |
| 3.4.3 | <i>Beck Depression Inventory</i> .....                    | 58 |
| 3.4.4 | <i>Questionnaire on Resources and Stress</i> .....        | 59 |
| 3.4.5 | <i>Family Support Scale</i> .....                         | 60 |
| 3.5   | <b>Statistical Analysis</b> .....                         | 62 |
| 3.5.1 | <i>Statistical Analysis</i> .....                         | 62 |
| 3.5.2 | <i>Hypothesis 1</i> .....                                 | 62 |
| 3.5.3 | <i>Hypothesis 2</i> .....                                 | 62 |
| 3.5.4 | <i>Hypothesis 3</i> .....                                 | 63 |
| 3.5.5 | <i>Hypothesis 4</i> .....                                 | 64 |
| 3.6   | <b>Power Analysis</b> .....                               | 67 |
| 3.7   | <b>Ethical Approval</b> .....                             | 67 |
| 4.    | <b><u>RESULTS</u></b> .....                               | 68 |
| 4.1   | <b>Hypothesis 1</b> .....                                 | 68 |
| 4.2   | <b>Hypothesis 2 (Child Characteristics)</b> .....         | 69 |
| 4.2.1 | <i>Hypothesis 2A</i> .....                                | 72 |
| 4.3   | <b>Hypothesis 3 (Mother's Characteristics)</b> .....      | 74 |
| 4.3.1 | <i>Hypothesis 3A</i> .....                                | 75 |
| 4.4   | <b>Hypothesis 4 (Environmental Characteristics)</b> ..... | 76 |
| 4.4.1 | <i>Hypothesis 4A</i> .....                                | 78 |
| 4.4.2 | <i>Hypothesis 4B</i> .....                                | 80 |
| 4.4.3 | <i>Hypothesis 4C</i> .....                                | 81 |
| 4.4.4 | <i>Hypothesis 4D</i> .....                                | 82 |
| 5.    | <b><u>DISCUSSION</u></b> .....                            | 84 |
| 5.1   | <b>Discussion of Results</b> .....                        | 84 |
| 5.2   | <b>Summary of Results</b> .....                           | 94 |

|            |   |            |
|------------|---|------------|
| <b>5.3</b> | <b>Methodological Issues.....</b>                   | <b>97</b>  |
| 5.3.1      | <i>Methodological issues with the design.....</i>   | <i>97</i>  |
| 5.3.2      | <i>Methodological issues with the sample.....</i>   | <i>99</i>  |
| 5.3.3      | <i>Methodological issues with the measures.....</i> | <i>101</i> |
| <b>5.4</b> | <b>Conclusions and Clinical Implications .....</b>  | <b>105</b> |
| <b>5.5</b> | <b>Suggestions for Future Research.....</b>         | <b>107</b> |

## REFERENCES

## APPENDICES

|             |  |
|-------------|--|
| Appendix 1  | Information and Invitation to Research (Research Subjects) |
| Appendix 2  | Information and Invitation to Research (Control Subjects)  |
| Appendix 3  | Consent Form   |
| Appendix 4  | Demographic Questionnaire                                  |
| Appendix 5  | Challenging Behaviour Questionnaire                        |
| Appendix 6  | Beck Depression Inventory                                  |
| Appendix 7  | Short Form of the Questionnaire on Resources and Stress    |
| Appendix 8  | The Family Support Scale                                   |
| Appendix 9  | Scoring Criteria for Non-Standardised Questionnaires       |
| Appendix 10 | Hypothesis 1 – Descriptive Data                            |
| Appendix 11 | Hypothesis 3 – Descriptive Data                            |
| Appendix 12 | Hypothesis 4 – Distribution of Number of Supports          |
| Appendix 13 | Hypothesis 4 – Distribution of Helpfulness of Supports     |

## FIGURES, GRAPHS AND TABLES

### Page Number

### FIGURES

|          |  |    |
|----------|--|----|
| Figure 1 | A model of the interaction between child's behaviour, parental stress and parenting behaviour..... | 24 |
|----------|--|----|

### GRAPHS

|            |   |    |
|------------|---|----|
| Graph H2.1 | The number of challenging behaviours reported by both groups..... | 71 |
|------------|---|----|

### TABLES

#### Demographics (Research Group)

|             |                                   |    |
|-------------|-----------------------------------|----|
| Table 3.3.1 | Research Group Demographics ..... | 52 |
|-------------|-----------------------------------|----|

#### Demographics (Control Group)

|             |  |    |
|-------------|--|----|
| Table 3.3.2 | Control Group and Research Group Demographics..... | 54 |
|-------------|--|----|

#### Measures

|             |  |    |
|-------------|--|----|
| Table 3.4.1 | Cut-off scores on the BDI.....               | 58 |
| Table 3.4.2 | Four factors of the QRS-F.....               | 59 |
| Table 3.4.3 | Sources of support indicated by the FSS..... | 60 |

#### Results

|            |   |    |
|------------|---|----|
| Table H2.1 | Challenging behaviour reported by the research and control group.....         | 70 |
| Table H2.2 | Mean number of challenging behaviours reported by mothers in both groups..... | 72 |
| Table H3.1 | The frequency of data in terms of severity of depression..                    | 74 |
| Table H4.1 | The number of sources of support indicated by each group on the FSS.....      | 76 |
| Table H4.2 | Total helpfulness of each area of support rated by each group on the FSS..... | 78 |
| Table H4.3 | Support required by mothers of children with learning disabilities.....       | 81 |

# **Abstract**

## **Introduction**

A unique inter-relationship exists between a child with learning disabilities and their environment. As the primary care giver, the mother of a child with learning disabilities is considered to experience significant stress in relation to caring for her child. This study investigates whether mothers of children with LD experience more stress than mothers of children without LD and identifies the exacerbating and moderating factors associated with the mother's experience of stress.

## **Method**

A total of 30 mothers of children with learning disabilities and 25 mothers of children without learning disabilities took part in the study. All participants lived in the Scottish Borders, a rural area with a population of 106 000. A questionnaire design was employed and data were collected during a semi-structured interview lasting approximately 30 minutes.

## **Results**

Results found that mothers of children with learning disabilities reported significantly higher levels of stress than mothers of children without learning disabilities. The number of challenging behaviours displayed by their child and maternal depression significantly exacerbated their experience of stress, while the perceived helpfulness of social support networks was a moderating factor.

## **Conclusion**

In conclusion, therefore, mothers of children with learning disabilities were significantly more likely to experience stress than mothers of children without learning disabilities. Contributing factors included, challenging behaviour and maternal depression, and stress was moderated by the presence of social support networks.

This study will inform clinicians of the difficulties inherent in bringing up a child with learning disabilities, especially in relation to stress experienced by the child's mother and the factors contributing to her experience. This in turn will inform clinicians that a child with learning disabilities cannot be treated in isolation, and that services need to be arranged to meet the unique needs of each individual and their family.

## **1. Introduction**

In 1986, Fewell described mental retardation, or learning disabilities, as it is more commonly referred to in the UK, as “probably the most dreadful diagnosis a parent can receive.” In the early 1980s research looking at the impact of a child with learning disabilities upon their family suggested that, mothers specifically, would experience stress, burden, social isolation and psychological dysfunction (Shapiro, 1983). Studies since then however, have identified that there are several mediating and moderating variables that appear to influence the mother’s experience of this relationship. A unique inter-relationship exists between the child and their environment and, in turn, between the child and its mother. In analysing a mother’s experience of stress therefore factors associated with the child, its mother and the environment play a significant role. Discussion of these factors will highlight their role in either exacerbating or moderating the mother’s experience of bringing up a child with learning disabilities.

## 1.1 Setting The Scene

### 1.1.1 What is a Learning Disability?

The term “intellectual disability” is socially constructed and, as such, what it means and how it is measured, has changed over time (Trent, 1995). In addition, definitions of “intellectual disability” vary in different countries (Fernald, 1995), and indeed within countries also. In the US, the term mental retardation is used and in the UK the term intellectual disability and learning disability are used inter-changeably. In the early 1990s Luckasson, Coulter, Polloway et al. (1992) revised the American Association on Mental Retardation (AAMR)’s comprehensive and widely accepted definition that remains in use to date. The important elements of this definition are:

- Substantial limitations in adaptive functioning, in at least two or more of the following areas; communication, self-care, home living, social skills etc.
- Significantly sub-average intellectual functioning, as defined by an IQ score of 70 or below
- Onset before the age of 18

The term learning disability will be used throughout this study.

### 1.1.2 Prevalence of Children with a Learning Disability in the UK

There are approximately 25 children per 1000 under the age of 16 with a learning disability in the UK (Woodroffe, Glickman, Barker et al. 1993). Of these, between 14 and 16 per cent will have a severe learning disability. Those with severe learning disabilities have increased health

needs such as, sensory difficulties; psychiatric problems; epilepsy and behaviour problems (British Paediatric Association, 1994).

### *1.1.3 Epidemiology of Learning Disabilities*

Several factors are implicated in the aetiology of intellectual disability. They include, Organic, polygenetic and socio-cultural factors. Organic causes include; chromosomal abnormalities such as Down's Syndrome; phenylketonuria; exposure to intrauterine infections such as rubella; exposure to intrauterine toxins such as alcohol; perinatal and postnatal complications. It is estimated that 50 per cent of the variation in intelligence is genetically transmitted accounting for polygenetic causes, whilst the link between social disadvantage and lower intelligence has long been established and accounts for socio-cultural causes (Neisser, Boodoo, Bouchard et al. 1996). Organic factors often explain the majority of moderate, severe and profound disabilities and polygenetic and socio-cultural factors are more likely implicated in the milder forms of intellectual disability.

### *1.1.4 Political Background*

The United Nations Conventions on the Rights of the Child stresses that disabled children have the right to lead a full and positive life and the Children Act (1989) highlights the importance of family based services for children that are comprehensive, flexible and accessible. Finally, the Scottish Office Review of Learning Disability Services, "The Same As You?" highlights that individuals with a learning disability should have access to services to meet everyday needs, extra needs associated with their learning disability and services to meet complex needs including behavioural difficulties.

### *1.1.5 Service Issues*

Currently children with learning disabilities fall between Child and Adolescent Mental Health Services and Adult Learning Disability Services, in most cases relying on paediatricians to manage their mental health and behavioural difficulties (Blair, Pullan, Rands et al. 2000). Across England and Wales, 71.9 per cent of adult learning disability services also provide a service for children with learning disabilities (Bailey and Cooper, 1997). The situation in Scotland, however, is quite different. Based on research conducted in 2001 by McKenzie, Paxton & Murray, 83 per cent of learning disability services provided by Scottish national health service trusts, did not have a paediatric service designed specifically for children with an intellectual disability and those areas that did were funded by the adult learning disability service. This highlights a significant need, particularly within Scotland, for services specifically addressing the needs of children with a learning disability.

The above discussion introduces the definition of a learning disability, the prevalence of learning disabilities among children in the UK, the epidemiology of learning disabilities and the political background and services issues that exist for this client group. This discussion serves to introduce some of the wider issues for children with learning disabilities and their families and introduces some of the potentially exacerbating factors likely to have an influence upon the stress experienced by the child's mother, such as, the prevalence of challenging behaviour in more severe learning disabilities and the lack of professional services available in Scotland for this client group.



## **1.2 The Child with Learning Disabilities and Their Environment**

### **1.2.1 The Child with Learning Disabilities**

The child with learning disabilities lives within a dynamic environment and the inter-relationship between the child and their environment allows us to understand the challenges that face the individual and those around them. Families of children with learning disabilities have been studied from two perspectives. The first perspective focuses upon the role of the family in the aetiology of mild learning disabilities and the other perspective focuses upon the impact the child with learning disabilities has upon its family.

In terms of the child with learning disabilities, several factors contribute to the impact they have upon their environment. These include, their ability to attach to their primary caregiver, the age and gender of the child, the severity of their learning disability, the presence of additional impairments and the presence or absence of challenging behaviour. Before discussing each of these factors in turn however, it is important to discuss the impact the environment has upon the development of the child in order to establish the true inter directional nature of this process

### **1.2.2 The Impact of the Environment**

Sameroff & Chandler (1975) claimed that a child's "developmental outcome is the result of a transaction between the child and their environment" (p191). Bronfenbrenner's (1979) ecological theory suggests that the child develops within a series of environments, the microsystem; the mesosystem and the exosystem. The microsystem describes the home or school environment,

the mesosystem encompasses two or more microsystems and the exosystem, the interaction of mesosystems. In terms of the child with learning disabilities, each of these systems has an impact either directly or indirectly upon their development. Crnic (1990) applied Brofenbrenner's (1979) systems to the study of processes within families with children with learning disabilities. Their approach suggested that, not only the child has an impact upon their environment but the stress experienced by a family with a child with learning disabilities may, in turn, have a detrimental effect upon the child itself. However, these stresses may be alleviated by social support, which may result in better developmental outcomes for the child. The parent's social friendship circle is an example of a mesosystem. This system therefore, potentially has a positive influence upon the child's parents (the microsystem) which in turn directly influences the child's development

Horowitz (1987) presents an alternative to Brofenbrenner's model. He describes functional relationships on four levels. The most basic level of the environment involves the stimuli array available to the child through all of their senses. At the next level, the environment provides a variety of learning opportunities, therefore providing the context for development and learning in addition to the stimulus array. The next level of the environment involves people themselves in the facilitation of learning opportunities, for example in the acquisition of language. The final and most complex level of the environment is the cultural context for development. This level determines how all other levels of the environment are permitted to function in relationship to the child. Individual differences come into play at each of these levels and influence how each child responds to each level. What constitutes a stimulating environment for one child may not be stimulating enough for another child or may be too stimulating for a child with perceptual limitations.

In summary, the interaction between the child and their environment is multi-directional in nature. In terms of the stress experienced by a mother with a child with learning disabilities therefore, several factors come into play and the lines of causality in terms of the impact these factors have upon the mother's experience of stress do not necessarily flow in one direction. The following discussion will look more specifically at the inter-relationship between the mother and her child with learning disabilities.

### **1.3 The Relationship between the Child and Their Mother**

#### ***1.3.1 The Inter relationship between the mother and her child***

Until the 1970s, research focused mainly on the impact the mother had upon her child's development (Bowlby 1958). In the 1970s, the reciprocal nature of the mother-child relationship was being acknowledged (Lewis & Rosenblum, 1974). This enabled researchers to look at, not only the impact the mother had upon her child, but the impact the child had upon their mother.

Bell (1968) studied the direction of effects in parent-child interactions and his work marked the beginning of the shift away from the uni-directional understanding of parent-child interaction towards a more bi-directional understanding. Bell's (1968) work highlighted that the mothers parenting style could be influenced by characteristics of her child such as temperament and responsiveness and, as such, mothers of children with learning disabilities were likely to display significantly different interaction styles than mothers of children of typically developing children. This illustrates how characteristics displayed by both the mother and her child are likely to have an impact upon the stress the mother experiences in relation to her child. This is illustrated in the following discussion about the bi-directional nature of the bond between the mother and her child, with specific reference to the role of the child with learning disabilities within this process and the impact this has upon the mother's experience of stress.

#### ***1.3.2 The Mother / Infant bond***

At birth, a child is equipped with several behavioural systems that can be activated, terminated, strengthened or weakened depending upon the stimuli available in the environment. Within

these systems are included the “building bricks” (Bowlby, 1958) for the development of attachment. These building bricks are displayed behaviourally through; looking, crying, sucking and clinging on a primitive level, through to smiling and babbling and eventually crawling and walking. These behaviours allow the child to orientate to their environment, signal to people within their environment and maintain proximity to the attachment figure. Both the child’s visual and auditory attention is encouraged by feedback and learning, as the infants attention is reinforced by his mothers attention and his mothers attention leads to an increase in the infants attention towards its mother. This mutually reinforcing relationship ensures that the vocal and auditory interaction between the mother and child increases.

The quality of attachment between a parent and their child and the way in which control and warmth are combined within the parenting style has significant effects on the child’s later psychological development and adjustment (Darling and Steinberg, 1993). Secure attachment to an attachment figure is a protective factor (Belsky & Nezworski, 1988), providing a child with security and a model upon which future relationships are based. It leads to the development of self-esteem, positive affect and a strong sense of personal autonomy.

Factors contributing to the bonding process between a mother and her child include the mother’s ability to pick up cues from her child and then to respond appropriately to these cues. Behaviours exhibited by a child that promote bonding include smiling, vocalizing, and eye contact and the display of these behaviours vary significantly in children with developmental disabilities, thus impacting upon the bond between them and their mother. Differences are apparent however, depending upon the type of disability affecting the child. This appears to be linked to the characteristics of the disabled child. Hoppes & Harris (1990) identified that the degree of responsiveness, affection and emotional closeness displayed by the child overall

influenced the nature of the relationship between the mother and her child. This was illustrated with mothers of children with autism and mothers of children with Down's syndrome. Behaviours displayed by children with autism, such as limited activity level, crying, lack of responsiveness and passivity are behaviours that discourage appropriate attachment (Minnes, 1998). The development of this bond between the mother and their child may be an important factor in the development of stress as is illustrated by families of children with autism who consistently report higher levels of stress than families of children with other developmental disabilities.

## 1.4 The Impact of the Child Upon their Environment

Research looking at the impact of raising a developmentally delayed child has increased considerably over the past twenty years. Early work provided a foundation upon which research on families of children with learning disabilities has grown.

### 1.4.1 The Developmental Perspective

The developmental perspective highlighted the “complex interplay” between family relationships and the interaction of family members, emphasizing the need to consider the family context itself and broader support systems. Theoretical models were developed to conceptualise the ideas that needed to be included in research of this nature.

#### **Double ABCX Model** (McCubbin & Patterson, 1983)

The double ABCX model is encapsulated in family stress theory. Family stress theory was developed in the late 1940s, early 1950s, by Hill (1958) as a result of his studies of families separated by the war. Family Stress theory (Hill, 1958) highlights the active processes families engage in to balance family demands with family capabilities, as these interact with family meanings to arrive at a level of family adjustment or adaptation (Patterson, 1993). From these studies, Hill (1958) developed his ABCX family crisis model. Hill (1958) postulated that A (the stressful event) interacting with B (the family’s resources for meeting the crisis) interacting with C (the definition the family makes of the event), produces X (the crisis). The double ABCX was developed in the mid 1980s by McCubbin & Patterson (1983) and is based upon Hill’s (1958) original ABCX model. It focuses on family events over time, therefore, the interaction of Aa

(the pile up of stressors), Bb (the resources families build up and employ to deal with the situation) and Cc (how these events are perceived during their period of adjustment) result in Xx (the outcome for the family, whether that be adaptation or maladaptation).

Both these models suggest that it cannot be assumed that having a child with a learning disability necessarily creates stress within the family. If a family has sufficient resources to cope with their child and can reframe their child's learning disability positively, they may not experience a feeling of crisis and will therefore, successfully adapt to the presence of their child within the family. The double ABCX model, however, recognises that a family's response to an event is a dynamic process as situations and available resources change over time.

#### *1.4.2 The Sociological Perspective*

The sociological perspective was introduced in the late 1950s, by Bernard Farber (1959). He believed that families made only the "minimal adaptation" to their own norms and roles that they felt necessary to maintain family equilibrium. Parents experienced high stress when discrepancies became apparent between role expectations and role performance for either themselves or their child and resulted in a period of transition. This may help to explain why, in some cases, middle class families experience a greater sense of loss and disappointment as they realise the greater discrepancy between their expectations for their child and the child's actual abilities. Farber (1959) explained that the child with disabilities fell behind and, regardless of their position within the family, adopted the role of the youngest child as more able siblings matured. This resulted in the parent's inability to move on from child rearing practices to pursue life goals.



#### *1.4.3 The Psychological Perspective*

The psychological perspective concentrated more upon the individual's adjustment to rearing a child with learning disabilities. Olshansky (1962) suggested that parents of children with learning disabilities experience a state of "chronic sorrow" in response to the birth of their child, which he defined as a long-term internalisation of a depressive mood which was a natural reaction to a tragic fact. Wikler, Wasow & Hatfield (1981) redefined Olshansky's (1962) perception of chronic continuous sorrow as more a periodic phenomenon resulting from periods of emotional stress occurring at significant transition points throughout their child's development

The developmental, sociological and psychological perspectives have provided the foundation for research in the last 30 years on the impact of the learning disabled child upon the family. In general, studies have found that parenting a child with learning disabilities, leads to the experience of more stress than that experienced within families of children without a learning disability. The following discussion will address this issue directly, focusing on the research literature in support of this. Following this, a discussion of the factors exacerbating and moderating the stress experienced by the mother of a child with learning disabilities will be presented, dealing with factors relating to the child, the mother and the environment.

## **1.5 Maternal Stress and The Child with Learning Disabilities**

A child with learning disabilities presents with lifelong impairment in cognitive and adaptive functioning. As a result of this, mothers of children with learning disabilities face complex problems, which, despite moves towards inclusion and normalisation, continue to be exacerbated by negative and stigmatic societal attitudes. Both affluent and deprived mothers experience stress in relation to their learning disabled child, although the stressors associated with, and resources available to cope with, their child vary considerably. Mothers can be affected socially, economically and emotionally by their learning disabled child (Schild 1971).

### ***1.5.1 Approaches to the Study of Stress***

The stimulus-response model views stress, as the result of an antecedant stimulus or event (Robinson, 1983). The life-events model views stress as the result of, or cumulative effect of, major life events (Dohrenwend & Dohrenwend, 1974) and the transactional model (Lazarus & Folkman, 1984a) views stress as the result of an individual's perception or appraisal of events and circumstances in relation to available resources. In the later model (Lazarus & Folkman, 1984a), the individual experiences stress when there is a mismatch between the demand and the resources available. This model has driven much of the research into stress experienced by mothers of children with disabilities.

### 1.5.2 The Process Model of Stress and Coping

The process model of stress and coping has been acknowledged as the most comprehensive model of stress, coping and adjustment (Beresford, 1994; Coyne & Smith, 1991). It was developed by Lazarus and Folkman (1984) in the mid 1980s and has been applied to research into families of children with developmental disabilities. This model recognises the *individual's* experience of stress as opposed to looking exclusively at family responses. In addition, the model advocates the role of intra-personal and socio-ecological factors in mediating the effects of stress and “conceives the individual as actively and creatively seeking to manage stress as it is encountered” (Beresford, 1994). The central tenet of the process model of stress and coping suggests that the process of coping mediates the effects of stress on individuals well being.

### 1.5.3 The Mothers Experience of Stress

The process model of stress and coping facilitates ones understanding of the stress experienced by the mother of a child with learning disabilities. Although it has been found that mothers of children with disabilities obtain rewards and satisfactions from care giving, these satisfactions are linked to, or are outcomes of, successful strategies for coping with potentially challenging situations (Grant et al, 1998). Difficulty coping with a child with learning disabilities, therefore, reduces the availability and range of rewarding and satisfying care-giving experiences.

It is well established that mothers of children with developmental disabilities experience chronic stress, (Weiss, 2002, Baxter, Cummins & Yiolitis, 2000, Dyson, 1997, Quine and Pahl, 1985). Weiss (2002) identified parenting a child with developmental delay as a “...long term, intense stressor that requires both short-term and long term problem solving skills” (p115). Mothers

often feel isolated from mothers of normally developing children as a result of the different experiences associated with bring up a child with disabilities (Seligman and Darling, 1997). In addition to isolation, parents may also experience fatigue, depression, lowered self-esteem and interpersonal dissatisfaction (Bristol, 1984).

Dyson, (1993) identified that the impact of a disability is not restricted to the individual but extends to all family members. Dyson (1993) found that stress in relation to a child with a disability was relatively stable and the impact upon family functioning was consistent over time.

Weiss (2002) described that the experience of stress was associated with factors relating to the child and the environment, for example, stress can be associated with the level of the child's disability (Donovan, 1988), or the presence of challenging behaviour displayed by the child (Quine & Pahl, 1985). In addition, the experience of stress can be associated with factors relating to the mother, for example, parental depression. Finally stress can be exacerbated or moderated by factors in the environment, for example socio-economic status and the level of support the family receive in relation to their child (Quine & Pahl, 1985; Beresford, 1994).

## **1.6 Factors Influencing The Mother's Experience of Stress**

The following discussion will be divided into three sections and will discuss the impact of the factors mentioned above. The first section will discuss factors associated with the characteristics of the child; the second section will discuss factors associated with characteristics of the mother and finally the third section will discuss factors associated with characteristics of the environment that have an impact upon the experience of stress for the child's mother.

### **1.6.1 Characteristics of the Child**

#### **Gender and Age of the Child**

Studies looking specifically at the gender differences and the age of the child with learning disabilities, and their impact upon the stress experienced by their mothers, have produced inconclusive results. Patterson (1980) found that boys with learning disabilities produced more stress within the family than girls. Additional studies have found that gender plays an important role in parental adjustment to the presence of a learning disabled child in the family (Frey, Fewell & Vadasy, 1989; Yau & Li-Tsang, 1999). Frey et al (1989) found that fathers were more affected by the gender of their child with learning disabilities than mothers. This was explained in terms of the father's expectations, for their child, especially their sons, in relation to their involvement in joint recreational activities as opposed to direct care-giving. With a child with learning disabilities, therefore, this traditional fathering role may be compromised. Other studies, however, have found no gender differences (Cummings, Bailey & Rie, 1966; Dumas, Wolf, Fisman et al. 1991). These discrepant results may be partly attributable to methodological shortcomings such as the absence of an appropriate control and socio-economic variability.

Studies looking at the age of the learning disabled child in terms of the stress experienced by mothers, have also proved inconclusive. Some studies highlight that younger children are more stressful than older children with learning disabilities (Mash & Johnston, 1983), while other studies report that older children create more stress in families than younger children (Bristol & Schlopler, 1984). Possibly more meaningful in terms of studying the impact the age of the learning disabled child has upon the family, is to look at periods of transition. Studies have identified that families experience increased stress in relation to their learning disabled child during specific stages in the family life cycle (Byrne & Cunningham, 1985) or during transition periods in the child's life cycle (Wikler, 1986). For example, at the birth of a learning disabled child, parents are likely to experience crisis (Fortier & Wanlass, 1984). Maternal stress is widely reported in the early years (Beckman, 1983) and disrupted family functioning has also been reported as the child grows older. This appears to be a result of financial burden and long-term uncertainty about the child's future (Harris & McHale, 1989).

Dyson, (1997) compared parental stress, and family functioning in parents of school age children with learning disabilities with parents of school children without disabilities. She found a high level of stability in maternal stress and some degree of consistency in family functioning over time in families of children with disabilities. By her own admission, Dyson (1997) recognises that participants were drawn from two parent families with middle class backgrounds and this may have had a significant impact upon the results obtained. In addition, this particular study focused on school-age children and as such parental stress and family functioning was not studied in relation to children, with learning disabilities, of pre-school age.

## **Level of Disability**

Many studies looking at the impact of having a learning disabled child, view these children as a homogeneous group (Wikler, 1986) and the distinction between mild, moderate and severe learning disability is not made. The results of these studies, therefore, have limited value and, as such, focus will be drawn towards studies where this distinction is made. Research looking at the stress experienced in relation to a child's level of ability remains inconclusive. Some studies identify increased stress in families of children with lower abilities (Frey, Frewell & Vadasky, 1989), whereas other studies report that stress is associated with higher levels of ability. Mink, Nihira & Meyers, (1983) studied families of children with moderate learning disabilities and found that the availability of social support services contributed to the development of five distinctive family types, ranging from close-knit families to disadvantaged families, thus suggesting that even within studies looking at one ability range, in this case moderate ability, there are differences apparent in the way in which a family might cope and this appears to be associated with levels of social support. Blacher, Nihira & Meyers, (1987) looked specifically at the impact of the child's level of ability upon the family. They found no significant differences in coping scores for parents of mildly, moderately or severely disabled children. In a study of mothers of moderately learning disabled children, Flynt & Wood (1989) found that mothers of children with moderate learning disabilities experience a high level of stress. Unfortunately in this study, the sample consisted of only mothers of children with moderate learning disabilities and therefore comparisons could not be made with mothers of children of different levels of ability.

Quine & Pahl (1985) expected to find that stress experienced by parents would vary according to their child's diagnosis. Therefore, children with Down's Syndrome, who can communicate and are mobile, were expected to be less stressful than children with cerebral palsy and a learning

disability, who are often immobile with multiple difficulties. However they found that this was not the case and in some cases the very opposite was found. This led Quine and Pahl (1985), to look at the nature of the impairment and the presence of multiple difficulties, which will be discussed below.

More recently, in contrast to the findings of Quine and Pahl (1985), characteristics associated with a diagnosis *have* been found to have an impact upon the stress experienced by families. A study conducted by Dumas et al (1991) found that mothers of children with autism and behaviour problems experienced more stress in their parenting tasks than mothers of children with Downs Syndrome and normal development. Hodapp, Dykens & Masino, (1997), in a study looking at the stress experienced by parents of children with Prader-Willi Syndrome, found that parents of children with Prader-Willi Syndrome reported higher levels of family problems than parents of children with mixed aetiology and this was associated with the specific challenging behaviours presented by those individuals with Prader-Willi. A discussion on the impact of challenging behaviour will follow.

### **Presence of Physical Disability / Sensory Impairment**

Few studies have looked at the impact of a child's physical and/or sensory impairment in relation to the stress experienced by the family. Quine and Pahl (1985), looking at the factors associated with stress in 200 families with a child with learning disabilities, found that the more impairments experienced by the child, for example, mobility problems, incontinence, sensory impairments, night time disturbance, behaviour problems, communication and the presence of epilepsy, the more stress experienced by those who care for them. The factors most strongly associated with stress in mothers were behaviour problems, night-time disturbance and multiplicity of impairments. This suggests that stress is not associated with physical



impairments or sensory impairments per se, but if these impairments are combined with other difficulties, this will increase the carer's experience of stress. One note of caution from Quine & Pahl's (1985) study is their exclusive use of families of children with severe learning disabilities. However, it is felt that they chose to look at one level of disability to reduce the complexity of their study and, in doing so, identified several factors that account for the variance in stress experienced by families of these children. This suggests therefore, that factors such as challenging behaviour and multiplicity of impairments may have a greater influence upon the stress experienced by mothers of children with learning disabilities than the level of disability. This is consistent with that found by Blacher et al (1987).

### **Challenging Behaviour**

Additional psychological needs of children with learning disabilities are consistent with those of children without a learning disability, presenting to a Child and Adolescent Mental Health Service. Taking a developmental perspective, these difficulties include; temper tantrums, feeding, sleeping and toileting difficulties in the early years and depression, anxiety, low self esteem and challenging behaviour displayed by those making the transition into adolescence. However, children with a learning disability are three to four times more likely to experience emotional and behavioural disturbance than those with an IQ within the normal range (Rutter, Graham & Yule, 1970; Bregman, 1991; Dykens, 2000). Gangadharan, Bretherton & Johnston, (2001) recognise that these children are at risk of developing a wide range of mental health problems, "the prevalence of which varies with the level of disability and the presence of additional disabilities" (p99). Children with more severe disabilities are at a higher risk of epilepsy and autism (Deb and Prasad, 1994; BPA, 1994), and additional disabilities include cerebral palsy and sensory impairments. A broad range of variables have been proposed to

account for these differences including genetic, neurological, socio economic and motivational factors.

Challenging behaviour refers to any behaviour's that pose a problem for services to manage. Hastings and Remington (1994) recognise three forms of challenging behaviour. These include, aggressive / destructive behaviour, for example, assaultative behaviour towards others or destructive behaviour towards objects within the environment; self-injurious behaviour, such as eye poking and head banging and finally, stereotypy, which includes repetitive or obsessional behaviour. In addition, other behaviours that may be classed as challenging include disruptive anti-social behaviour, such as, stripping, screaming in public or running away and finally, overly passive behaviour. Behaviour of this nature proves challenging for services as children are seen as withdrawn and / or non-compliant and therefore their access to services is limited.

It is widely acknowledged that parents of children who display challenging behaviour are more likely to experience stress. Quine & Pahl (1985) identified that stress in mothers is most strongly related to the presence of behaviour problems in their child. These behaviour problems included, temper tantrums, destructiveness, night-time disturbance, spitting, biting, screaming, wandering, and sexual delinquency. In addition, the more severe the behaviour problems, the more stress the mother was likely to experience. The problems parents highlighted in relation to the difficulties they had included: difficulty keeping the child occupied; difficulty managing the child and not getting adequate amounts of sleep. In a study conducted by Dumas (1991), it was found that mothers of children with autism and behaviour problems perceived themselves as experiencing more stress in their parenting tasks than mothers of children with Down's Syndrome and mothers of children with normal development. However, Dumas (1991) failed to

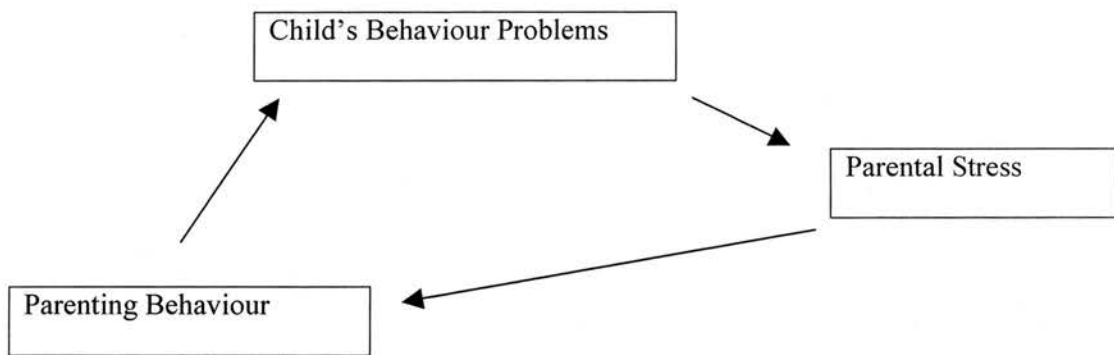
match parents for socio-economic status and single parenthood, both factors that may influence a mother's experience of stress.

More recently, a study conducted by Hodapp et al (1997), looking at the experience of stress in mothers of children with Prader-Willi Syndrome, found that parents reported higher levels of family problems than parents of children with mixed aetiology. It was argued that this was associated with the high rates of psychopathological behaviours present in individuals with Prader-Willi Syndrome. However, Hodapp et al (1997) failed to include a group of mothers with children with mixed etiology in their study and compared their findings to those of studies conducted some four to nine years previous. In addition, by their own admission, participants were selected from Prader-Willi parent groups and families were predominantly two parent and from middle class backgrounds and may not have been representative of the population as a whole.

To date, little work has been done on family processes in the development and maintenance of challenging behaviour. Hastings (2002) discusses the relationship between parental stress and behaviour problems in children with developmental delay. Oliver (1995) argued that children and parents reciprocally influence each other. He identified the relationship between coercive parenting styles and conduct problems in children and illustrated that challenging behaviour in turn is aversive to parents and, escape from these behaviours acts as a reinforcer. Hastings (2002) proposed a model to explain the interaction between a child's behaviour problems, parental stress and parenting behaviour (Fig 1).

Figure 1

A model of the interaction between behaviour problems, parental stress and parenting behaviour



Source: Hastings (2002)

An expanded version of Hastings' (2002) model introduces key variables affecting this interaction between the child's behaviour problems and parental stress. These include parental psychological resources. However, he suggests that further research needs to address more fully the integration of these issues and to recognise the impact of additional variables that may have an impact upon the integration of parental stress and challenging behaviour, for example, socio-economic status, family membership and maternal depression.

There is much empirical support for the notion that where children with developmental disabilities display more challenging behaviour, their parents are more likely to report increased levels of stress (Baxter et al, 2000; Blacher et al, 1997). However there is some debate as to the causality of this relationship. Hastings (2002) claims that there is "reasonable evidence that behaviour problems are associated with parental stress over and above the impact of other salient factors" (p152).

The causal mechanism of challenging behaviour leading to stress may result from the impact challenging behaviour reportedly has upon attachment. The more severe the learning disability, the higher the prevalence of challenging behaviour (BPA, 1994). Our preceding discussion on the mother – infant bond suggests that children with severe learning disabilities are less likely to display the attachment behaviours that encourage a mother and her child to bond. If, in addition to this, the child with severe learning disabilities is more likely to display behaviours that the mother will find challenging then this too will have a negative impact upon the attachment between the mother and her child. Janssen, Schuengel & Stolk, (2002) argue that it is this insecure attachment bond that elicits the development of challenging behaviour. It has been identified that challenging behaviour displayed by their child can cause an increase in stress experienced by the family, but, Janssen et al (2002) would argue that it is the insecure attachment between the mother and her child which is likely to lead to the development of challenging behaviour in her child. This presents a very uni-directional view of the development of challenging behaviour, and fails to recognise the role challenging behaviour plays in the development of insecure attachment. Both Hastings (2002) & Janssen et al (2002) present uni-directional models to explain the development of challenging behaviour and it is suggested that this is a reductionist approach to take when there are multiple factors having multiple bi-directional influences upon challenging behaviour, parenting behaviour and parental stress.

### **Summary**

This discussion has identified characteristics associated with the child with learning disabilities that may increase the likelihood of the family experiencing stress. These have included, the gender and age of the child; the level of the child's disability; the presence of multiple impairments in the child and the presence of challenging behaviour. In summary, the individual characteristics that appear to have the most significant impact upon the stress experienced by the

family, are, the presence of multiple impairments and challenging behaviour. However, referring back to the inter relationship between the mother and her child, both of these factors play an important role in the attachment process between the mother and her child and the bond between a mother and her child plays a significant role in the protection from, or development of, further difficulties.

In terms of the literature dealing with child characteristics, it appears that mothers of children with learning disabilities will report more challenging behaviours than mothers of children without learning disabilities and the presence of challenging behaviour and sensory and physical impairments will exacerbate the stress experienced by mothers of children with learning disabilities.

#### *1.6.2 Characteristics of the Mother*

##### **Parental Responses to the Diagnosis of developmental delay in their Child**

Partington (2002) examined maternal responses to the diagnosis of learning disability in their child. He identified two models to describe this maternal response, a personal and an interpersonal model. The personal model suggests that adjustment is mainly a problem concerning the mother. Whereas the interpersonal model suggests that adjustment has social dimensions. The double ABCX model (McCubbin & Patterson, 1983), discussed above, helps to explain the variability in the adaptation of the family to a learning disabled child over time. This highlights that the pile up of stressors associated with the child's disability (Aa), the family's resources built up by the family over time (Bb) and the family's perception of the child (Cc), interact to determine the extent to which the family adapts to their situation (Xx).

James (2001) identified that 50 per cent of mothers were dissatisfied with the way professionals delivered the news of their child's disability. Alexander and Klein (2000), highlight that this dissatisfaction may be a result of the anxiety clinicians experience in relation to giving such distressing information. Partington (2002) explored the experiences of women receiving antenatal or postnatal diagnosis regarding their child having a learning disability, in a focus group setting. He found that mother's dissatisfaction was associated with two areas, antenatal diagnosis and communication from professionals. If difficulties were discovered ante-natally, mothers felt that there was a lack of objectivity from nursing staff. Information from professional staff centred around termination and was framed within a pessimistic outlook for the future. Mother's dissatisfaction with professional communication focused on an overwhelming sense of disempowerment and depersonalisation. The over use of vague terms such as "developmental delay" and professional jargon did not facilitate the mothers understanding of her child's difficulties and promoted "shopping around" for diagnoses. In addition, receiving conflicting opinions from professionals led to a feeling of disempowerment. It is highlighted, however, that Partington's (2002) results are based upon a focus group of six mothers all with pre-school age children. Their responses, therefore, may not be representative of the population as a whole due to the small sample size and the limited age range.

Parental reactions to the diagnosis of developmental disabilities in their child vary considerably, depending upon factors such as personality; the nature of parents marital interactions; parental aspirations for themselves and their child and socio economic status. Despite these factors influencing a wide range of responses towards their child with learning disabilities, some reactions to their child's diagnosis are common, for example, guilt; ambivalence; anger and disappointment. Sylvia Schild (1971) recognised guilt as one of the most common reactions of parents to the diagnosis of learning disability in a child. Feelings of guilt develop in response to

primary feelings of rejection, hostility and destructiveness towards their child. Mothers often feel guilty about their behaviour during their pregnancy and will often blame themselves for their child's difficulties. Most feelings of guilt however, appear to be a normal response to dealing with unanswerable questions relating to the occurrence of the disability. Parent's feelings towards their child, however, are rarely stable or consistent. These inconsistent feelings influence the way in which a parent responds to their child, leading to parents swinging between patterns of over indulgence, over-protection, authoritarianism, and rigid child rearing practices.

Partington's (2002) study looked at the cycle of bereavement experienced by mothers after they had received their child's diagnosis. He identified that mothers experienced a wide range of emotional responses, including, loss, anger, guilt and sadness and found that these responses were not limited to the time immediately following diagnosis. This supports the view of Bruce, Schultz, Smyrnois et al. (1994) & Bruce, Schultz & Smyrnois, (1996), who found that parents experience ongoing feelings of loss and grief associated with their child with learning disabilities. In Bruce et al's (1994) study, they found no differences in the mother's experience of grief across several childhood age cohorts. This contradicts earlier findings that mothers resolve their grief six to eight weeks after receiving their child's diagnosis (Kennedy 1970). Bruce et al (1996) also discovered that the mother's reaction to their child's diagnosis was different to the father's reaction. Mothers were more likely to have intrusive thoughts about their child, they actively tried to avoid the distress that thinking about their child elicited and they experienced higher emotional distress associated with recall of the time they received their child's diagnosis. This differing grief response can be explained by Dyregrov & Matthieson (1987) who suggest that these gender differences may occur as a result of the difference between the mother and father's attachment to the child, different ways in which males and females react to stress, males under-report or failure to recognize emotional states and the different social



situations mothers and fathers find themselves in after the birth of the child and as the child develops. Bruce et al (1996) highlights the need for psychological intervention in view of the implications these gender differences may have upon marital relationships.

Not surprisingly gender differences also exist between mothers and fathers perception of family stress, social support and care giving demands in families of children with learning disabilities. In her study looking at the differences between mothers and fathers views on these factors, Beckman, (1991) reported that mothers were more likely to report stress within the family than fathers. Mothers also reported more depression, restrictions on the parental role, more effects on their relationships with their spouse and more effects on their health, whereas fathers reported more difficulty attaching to their child. In terms of support, both fathers and mothers identified informal support as a mediator of family stress. Care giving requirements were not associated with an increase in stress in fathers, however mothers reported restrictions on the parental role and a sense of incompetence relating to their care giving role. These results were supported by Krauss (1993). However she found no differences in depression as reported by each parent. These gender differences may also be explained by Dyregrov & Matthieson's (1987) views on the gender role relationships to the reaction to a child with learning disabilities living at home.

The factors discussed above, relating to dissatisfaction with professionals handling of the diagnostic process and grief experienced by parents, increase the likelihood of the experience of stress within a family, and especially for the mother, where a child has learning disabilities. This may help to explain why mothers of children with learning disabilities are more likely to experience depression.

## **Depression**

The research looking at the experience of depression in parents of children with a learning disability is variable and largely focuses on the mother's experience of depression. If mothers of children with learning disabilities experience ongoing loss and grief associated with their child (Bruce et al, 1994; 1996), this in turn is likely to lead to a greater risk of developing depression, and depression itself is likely to exacerbate an individuals' experience of stress. Although several studies support the presence of depression in mothers of children with learning disabilities, (Hoare, Harris, Jackson et al. 1998; Veisson, 1999) few studies have looked at the father's experience of depression and those that have, have found normal depression scores in this population.

It is argued that between 35-53 per cent of mothers of children with learning disabilities, on the Beck Depression Inventory (Beck et al, 1996), score within the mild, moderate and severely depressed ranges (Hoare et al 1998 & Veisson, 1999). Veisson, (1999) found that mothers of children with learning disabilities had higher levels of negative emotions and a lower level of positive emotions than controls. This study, however, was conducted in Estonia in 1999, a country undergoing significant social and economical change. Caution must be taken therefore in generalising the results of this study. Hoare et al (1998), found that maternal depression was closely linked to characteristics of the child with learning disabilities, especially the child's level of ability. Sanders & Morgan (1997), supported this view and found that mothers of children with autism were more likely to be depressed than mothers of children with Down's syndrome. This was supported by Scott, Sexton, Thompson et al. (1997), who reported low levels of psychological distress in mothers of children with Down's syndrome. They suggest that this may be due to the fact that parenting a child with Down's syndrome may be less stressful than parenting a child with other learning disabilities. In their sample all of the parents were

receiving professional services in relation to their child and this in turn may be ameliorating the parents experience of stress.

Olsson & Hwang (2001) found that mothers of children with autism were more likely to be depressed than mothers of children with other learning disabilities, who in turn were more depressed than a control group of mothers for who there were no concerns about their child's development. As mentioned previously, this may be associated with several challenging behaviours associated with autism that may have an impact upon the bond between the child and their mother. Olsson & Hwang (2001) recognise that their results are based upon a single administration of the BDI and that future studies should conduct repeated measures to identify the stability of such difficulties and the factors that may be associated with the emergence from depression in this sample group.

### **Cognitive Explanation for the experience of depression in parents of children with learning disabilities**

The cognitive theory of depression suggests that the individuals experience of depression relies upon the meaning the individual places upon the stressful event and, this in turn, will determine the impact this event has upon the individual (Beck, 1987). It is argued that if the event intrudes upon an individuals self perception, they are more likely to experience depression. An individual with pre-existing dysfunctional schemas is particularly sensitive to feelings of loss, helplessness and guilt, all of which are likely to be provoked by having a child with learning disabilities and as such, they are likely to be at greater risk of the activation of these dysfunctional schema. However, some mothers of children with learning disabilities may have been vulnerable to depression prior to the birth of their child with learning disabilities in which case their depression may have been activated by another stressor or indeed have remained

inactive in the absence of stressors. However, one cannot forget the fact that women are more likely to experience depression than men regardless of having a child with learning disabilities or not (Brown & Harris, 1978).

### **Maternal depression and care-giving**

The aim of this discussion has been to look at the presence of depression in mothers of children with learning disabilities, and assume that the mother's depression has been elicited by the activation of dysfunctional schemas of loss, hopelessness and guilt associated with her child with learning disabilities. However, the causal nature of this relationship between the mother's experience of depression and her child's learning disability is debatable. A brief discussion on the effects of maternal depression on parenting ability in general will be presented in an attempt to present a fair analysis of this issue.

Downey & Coyne, (1990) would argue that living with a mother with depression has serious consequences for many children and increases the risk of their child developing a number of developmental and adjustment problems. Not only are children of depressed mothers more likely to experience a number of psychiatric difficulties themselves (Lovejoy et al, 2000), they are also at higher risk of social and achievement deficits (Anderson & Hammen, 1993). This may be partly explained by the impact depression can have upon the mother's parenting skills. Lovejoy et al (2000) conducted a meta-analysis on the association between depression and parenting behaviour and found that negative or coercive maternal behaviours were positively associated with depression especially irritability and hostility. This association was strongest amongst mothers who were currently depressed, although residual difficulties are likely between mothers and their child after their period of depression. These effects were found to be particularly salient in samples of disadvantaged women and mothers of infants. There is little

research looking at the impact of a depressed mother upon a child with learning disabilities, however, depression is likely to serve only to weaken the already difficult bond between a mother and her child with learning disabilities and maternal depression has been considered a risk factor for children's development (Murray & Cooper, 1996). Kurstjens & Wolke (2001), however, found that maternal depression per se did not have negative effects upon a child's cognitive development, but long-term effects may be found when maternal depression is chronic, if the child is male or the family suffers from additional social stressors.

### **Summary**

This discussion has highlighted the maternal characteristics that may exacerbate the experience of stress for the mother of a child with learning disabilities, focusing largely on the mother's experience of depression and the possible origins of this. Maternal depression plays an important role in the experience of stress. However the causality of the relationship between stress and depression cannot be assumed to be in one direction.

With regard to the literature looking at maternal depression, it is argued that mothers of children with learning disabilities will report higher scores of depression than mothers of children without learning disabilities and within a group of mothers of children with learning disabilities, stress will be positively correlated with depression.

The following section will deal with environmental factors that influence the experience of stress in a mother with a child with learning disabilities. Having dealt almost exclusively with exacerbating factors so far, this discussion will illustrate the importance of environmental factors in the exacerbation *and* amelioration of stress. Family functioning styles, family membership and socio-economic status will be discussed in terms of their impact upon stress experienced

within the home of a child with learning disabilities. In addition, a discussion on coping and support will follow which will highlight the ameliorating effects of the environment upon the mother's experience of stress.

### *1.6.3 Characteristics of the Environment*

#### **Family Functioning Styles**

Adaptive family functioning and positive family relations have consistently been associated with positive maternal adjustment and a decreased sense of maternal burden (Kraus, 1993 & Sloper, Knussen, Turner et al. 1991), decreased levels of depression (Rousey, Best & Blacher, 1992) and parenting competence (Fagan & Schor, 1993). Family functioning is optimised when there are sufficient levels of family support and marital satisfaction. It has been suggested that security and satisfaction within a marital relationship is the best predictor of coping success in mothers of children with learning disabilities (Friedrich, 1979). Olson, McCubbin, Barns et al. (1983) found that high marital strength was a critical pre-requisite to predicting adaptation to a crisis situation. In a study conducted by Frey et al. (1989), support from spouses affected the way in which the partner perceived the disabled child. In this study, they found that mothers whose spouses had a more positive view of the child were more positive themselves.

#### **Family membership**

In terms of marital status and the experience of stress in relation to bringing up a child with learning disabilities, Beckman (1984) found that single mothers experienced more stress in relation to supporting their learning disabled child than did mothers from two parent families. In addition, Blacher & Lopez (1997) found that single mothers reported more depressive symptoms. However, other studies have found no relationship between marital status, maternal

stress and psychological adjustment in families of children with learning disabilities (McCubbin & Hwang, 1989). One study, conducted by Fagan & Schor (1993), found that marital status per se did not predict maternal satisfaction and adjustment, but the presence of adult companionship did. Therefore it cannot be assumed that a single mother is struggling, especially if she has alternative sources of adult companionship or support.

Mothers of children with learning disabilities frequently report an increased sense of burden than do comparable groups of mothers of children without learning disabilities (Bailey, Blasco & Simeonsson, 1992). This sense of burden can be increased by having a large number of dependent children in addition to the child with learning disabilities. This may be associated with the increased care needs of young children, or indeed the financial burden associated with having a large family. This imposes a sense of restriction and limitation upon the mother in terms of the freedom to pursue personal interests or maintain friendships. This increased burden leaves the mother at increased risk of maladjustment and maternal depression (Wallander, Pitt & Mellins, 1990; Erikson & Upshur, 1989).

### **Socio-economic status**

Socio-economic status refers to the financial status of the family. Low socio-economic status can be a stressor in itself in terms of low employability, poor housing and bad health. However the presence of a child with learning disabilities within a family that is already financially stretched can exacerbate their difficulties significantly.

Barber, Turnbull, Behr et al. (1988) identified that parents with higher levels of education coped more effectively with their child with developmental delay. Quine & Pahl (1985) supports this finding. They identified that mothers in families with higher incomes reported significantly less

stress on the Malaise Inventory than mothers with lower incomes. This assumes, however, that income and educational level are related in determining socio-economic status. In addition, a study by Breslau, Staruch & Mortimer, (1982) found that depression was negatively correlated with education and income.

Socio-economic status can influence the way in which a learning disability is interpreted (Farber, 1960). Middle class parents may view the presence of a learning disability in their child as a tragic crisis, preventing occurrence of normative achievement. This is associated with expectations and aspirations a family may have for their child and the realisation that these expectations may have to be adapted in some way. A family from a lower social class however, may become involved in a reality crisis, where already limited resources must be further strained. This may lead to the likelihood of siblings being more involved in care taking duties to relieve the burden of care.

### **Coping and Support**

The presence of a child with a chronic disability is a stressor that requires an ongoing coping response by the parents (Friedrich, Wiltturner & Cohen, 1985). It has been discussed so far that factors associated with the child, such as the presence of challenging behaviour; factors associated with the mother, such as, depression; and factors associated with the environment, such as, socio-economic status may exacerbate a mothers experience of stress and have a negative impact upon their ability to cope. These are clearly interrelated variables and the relationship between them is multi directional. However, we have yet to look at strategies employed by families to ameliorate the impact of these variables. This discussion will focus specifically on the use of cognitive coping strategies and the use of social support networks in mediating stress within families.



### Resiliency Model

A families' problem solving, coping strategies and family adjustment can be analysed with reference to the resiliency model of family adjustment and adaptation (McCubbin, Thompson & McCubbin, 1996). The resiliency model seeks to answer why some families cope in the face of crisis while other families don't. It attempts to understand the family strengths and capabilities which buffer the family from disruptions associated with normative family transitions, for example, moving house and non-normative stressors, for example, the birth of a child with learning disabilities. Resilience means to remain healthy in the face of risk and adversity. For the purposes of this study, resiliency means the degree to which families successfully fulfil their functions and one set of important factors highlighted by the model are the problem solving and coping strategies employed by the family when confronted with a stressor. In her review of coping resources and strategies, Beresford, (1994), emphasises the importance of personal and socio ecological coping resources. She identified that coping resources are a crucial aspect of the coping process that accounts for the variance in psychosomatic complaints and psychological distress (Beresford, 1994). If resources are unavailable, the individual is more vulnerable to stress.

### Personal Coping Resources

These include, physical health; beliefs and ideologies and parenting skills

- Physical health

If physical health is poor this can increase the individuals vulnerability to stress. The most common physical health problem reported by mothers of children with learning disabilities is lack of sleep. Over two-thirds of mothers reported being woken by their child at least once a week (Quine & Wade, 1991). Repeated disturbed nights can have a significant impact upon the parent's mood and energy. In addition, a national survey conducted by Meltzer, Smyth &

Robus, (1989) identified that, of a group of parents caring for a learning disabled child, over one third of mothers reported that having a learning disabled child had adversely affected their health. It is important to note that this included symptoms of both physical and mental ill health and, with regard to symptoms of mental ill health, this reflects the discussion on the experience of depression in mothers of children with learning disabilities.

- Beliefs and Ideologies.

Adopting positive approaches towards their child with learning disabilities will increase a families coping resources in relation to their child. Turnbull, Brotherson & Summers, (1985), identified that a mothers ability to focus on the positive aspects of their child and their situation led to positive family adaptation. In addition, the extent to which parents adopted a day-to-day, live for the moment type approach rather than planning for the future (Deaton, 1985), also enabled them to adapt more positively to their learning disabled child. McCubbin et al, (1996) found that active reinterpretation of events surrounding the family explains variability in family adjustment. Lustig (2002) looked at the relationship between a families problem solving and coping strategies, and family adjustment in families of children with and without a disability and found that a greater use of reframing family problems and less frequent use of family passivity was associated with higher levels of family adjustment. These findings provide strong support for the importance of cognitive appraisal in the coping model proposed by Lazarus and Folkman (1984), which suggests that when a parent or family reframes their situation in a positive way, they are better equipped to adapt more positively to their circumstances.

In a study by Tunali & Power (2002), it was found that mothers respond to the uncontrollable stress of raising a child with autism by “redefining what constitutes the fulfilment of various human needs” (p25). Mothers redefined their role in terms of their careers, their marriages, their

leisure time and their role as a parent. It is argued that if mothers redefine their roles, they are reported to experience an increase in satisfaction associated with bringing up their child. This approach is consistent with cognitive dissonance models (Festinger, 1957). Cognitive dissonance refers to an unpleasant internal state resulting from perceived inconsistency among aspects of knowledge, feelings and behaviours. People aim to reduce cognitive dissonance wherever possible and, as such, this explains why parents of children with learning disabilities redefine their own personal aspirations. By redefining what constitutes the fulfilment of basic human needs, mothers of children with autism can reduce any dissonance that might result from positive threats to these needs.

- Parenting skills

Parenting skills include, discipline; supervision; communication and negotiation with the child (Webster-Stratton, 1991). These parenting skills become more difficult to employ with a child with learning disabilities due to the presence of communication difficulties. However, effective behavioural management strategies can improve parent child relationships. Children with learning disabilities exhibit increased rates of behaviour and sleeping problems. Quine & Pahl, (1989) identified that enhancing parents skills to deal with behaviour and sleep difficulties can benefit both the parent and the child.

### Socio-ecological Coping Resources

Although personal resources are very important in mediating the effects of stressors, the use of socio ecological coping resources, specifically the use of social support, is of particular relevance to this study.

- Social Support

Schilling et al, 1984, defined social support on three levels:

1<sup>st</sup> level – close family members and friends

2<sup>nd</sup> level – neighbours and distant friends

3<sup>rd</sup> level – infrequent support e.g. formal support

Barrera & Ainlay, (1983) identified the function of social support in terms of emotional support, information, practical help and encouraging feelings of normality. These functions are met by each of the members encompassed by each level of social support. In terms of the first level of support, Beresford (1994) described the importance of spousal support. Spousal support was related to positive outcomes in mothers *and* fathers of children with learning disabilities (Sloper et al, 1991) and was identified as the most important form of support by Byrne, Cunningham & Sloper, (1988). The extended family could be viewed as second level support. Beresford & Lawton, (1993), identified that practical support in the form of childminding provided by extended family can be very important and can serve to maintain marital integration and satisfaction (Lee, 1979). Finally formal agencies such as health, social and education services represent third level support. Formal agencies tend to relieve the burden on informal levels of support, although most parents do not view formal services as providing emotional support (Florian & Krulik, 1991). Unfortunately, however, the majority of parents with children with learning disabilities are not receiving all of the services to which they are entitled (Parker & Lawton, 1991). This may be due to lack of information regarding services available to them (Ayer, 1984) or may be due to the lack of service provision for this client group, specifically in Scotland (McKenzie et al, 2001).

In a study by Philip and Duckworth (1982), parents of children with learning disabilities were found to perceive themselves as lonely and socially isolated. Social isolation can be one of the most stressful factors associated with caring for a child with learning disabilities (Quine & Pahl, 1985). Social isolation can occur for a variety of reasons. Challenging behaviour displayed by

their child, may prevent parents from developing and maintaining an active social life (Meltzer et al, 1989). Fatigue associated with lack of sleep and meeting the daily demands of their child, may preclude parents from maintaining friendships (Gough, Li & Wroblewska, 1993). Finally, stress can limit the parent's ability to negotiate social support (Quine & Pahl, 1985). This isolation is likely to increase levels of stress for mothers of children with learning disabilities and heighten the risk of depression.

The size and density of the social support network can influence how helpful the network is perceived by the child's parents. Studies looking at support networks for families with a child with learning disabilities are inconclusive. Some studies suggest that larger social support networks offer better support (Kazak & Wilcox, 1984). Whereas other studies suggest that it is the perception of the helpfulness of the support offered that is important as opposed to the size of the network itself (Florian & Krulik, 1991). Availability of social support and satisfaction with that support predicted adjustment for both fathers and mothers of children with developmental delay (Frey et al 1989). Parental satisfaction with support and the number of sources of support, were shown to be positively related to family integrity and lowered family stress (Dyson & Fewell, 1986).

### **Summary**

This discussion has illustrated the impact of environmental characteristics such as family functioning styles, family membership and socio-economic status, upon stress experienced by families of children with learning disabilities. Positive family relationships, particularly between parents, appears to be a significant protective factor in terms of coping with bringing up a learning disabled child. This helps to explain why single mothers can experience heightened stress, although this cannot be assumed, especially when she has alternative sources of adult

companionship and support. In addition, socio-economic status appears to be a significant environmental predictor of stress experienced by families of children with a learning disability and this appears to be associated therefore with limited resources and limited access to services and support. Finally, adaptive family functioning appears to ameliorate the experience of stress, particularly in mothers, and it is argued that family functioning is improved where there are adequate supports.

Within mothers of children with learning disabilities, therefore, heightened stress will be associated with marital status, increased numbers of children living at home and low socio-economic status.

In addition, this discussion has illustrated characteristics of the environment that may serve to ameliorate the experience of stress for mothers of children with learning disabilities, in particular, the importance of personal and socio-ecological coping resources in ameliorating the effects of bringing up a child with learning disabilities. In addition to physical health, personal beliefs and ideologies and parenting skills, social support appears to be the most significant buffer in terms of reducing the stress experienced by family members in relation to their child with learning disabilities. Support from one's spouse, has been identified as the most important form of support, by Byrne et al (1988). However extended families and formal agencies also provide invaluable support. Support alleviates the experience of social isolation faced by mothers of children with learning disabilities, which in turn reduces a mother's experience of stress and depression. In terms of the size of support networks, it remains inconclusive whether larger support networks are more helpful, or indeed whether it is the perceived helpfulness of the support that is important.

The literature relating to social support in mothers of children with learning disabilities suggests that mothers of children with disabilities may experience isolation and therefore access fewer social support networks than mothers of children without learning disabilities. However, it is likely that they will be in contact with more professional services than mothers of children without learning disabilities. In addition, the number of support networks and the perceived helpfulness of these supports are likely to be negatively correlated with stress.

## **1.7 Introduction to Research**

Several factors have been discussed in relation to their impact upon stress experienced by the mother of a child with learning disabilities. These factors appear to have either an exacerbating or ameliorating effect upon the mother's experience of stress. Those exacerbating factors that have been identified include, characteristics associated with her child, characteristics associated with the mother and characteristics associated with the environment in which they live. In addition, in terms of characteristics of the environment, they too can have an ameliorating effect upon her experience of stress, namely her use of social support networks. Due to time restrictions imposed upon this piece of research, a full analysis of all the factors discussed would be impossible. Therefore, a comparison of reported stress in mothers of children with learning disabilities with a control group will be conducted and a selection of the most pertinent factors influencing this experience of stress will be analysed in relation to their impact upon the mother's experience of stress. These factors will include, factors relating to the child, for example the presence of sensory and physical impairments and challenging behaviour; factors relating to the mother, for example, the presence or absence of depression; and factors relating to the environment, for example, marital status, socio-economic status, the number of children living at home, and the presence of social support networks.



## 1.8 Aims of this Study

The literature suggests that mothers of children with learning disabilities experience a significant amount of stress that can be explained in terms of the child's characteristics, the mother's characteristics and characteristics of the environment. However this experience of stress can be mediated by coping strategies, such as the availability and use of social support.

The studies cited in the literature review clearly indicate that mothers of children with learning disabilities experience more stress than mothers of children without learning disabilities, however, few studies conducted in the UK have looked at the influence of factors associated with the child, their mother and the environment upon the mothers experience of stress. The aim of this study, therefore, is to compare the experience of stress in a group of mothers of children with learning disabilities with a group of mothers of non-disabled children, and to identify the impact of:

- Characteristics of the child, such as, the presence of challenging behaviour and / or multiple impairments
- Characteristics of the mother, such as, her experience of depression
- Characteristics of the environment, such as, socio economic status, and social support

upon their experience of stress.

## **2. Hypotheses**

The following hypotheses will be tested:

1) Mothers of children with learning disabilities will experience more stress, measured by the QRS-F (Appendix 7), than mothers of children without learning disabilities.

### **Child Characteristics**

2) Mothers of children with learning disabilities will report more challenging behaviour displayed by their children, as measured by the informal challenging behaviour questionnaire (Appendix 5), than mothers of children without learning disabilities.

a) Within the group of mothers with children with learning disabilities, high levels of stress, as measured by QRS-F scores, will be associated with:

- Presence of sensory and physical impairments
- Presence of challenging behaviour and the number of challenging behaviours indicated.

### **Maternal Characteristics**

3) Mothers of children with learning disabilities will be at higher risk of depression, as measured by the BDI (Appendix 6), than mothers of children without learning disabilities.

a) Within the group of mothers with children with learning disabilities, high levels of stress, as measured by QRS-F scores, will be associated with:

- Presence of depression as measured by the BDI.

### **Environmental Characteristics**

4) Mothers of children with learning disabilities will use less social support networks, as measured by the Family Support Scale (Appendix 8), although they will use more professional services, than mothers of children without learning disabilities.

a) There will be no difference between the helpfulness of supports indicated by mothers of children with learning disabilities and mothers of children without learning disabilities

b) There will not be an association between the number of supports received and their perceived helpfulness.

c) Mothers of children with learning disabilities will report an insufficient degree of support in general.

d) Within the group of mothers with children with learning disabilities, single mothers will report more stress than married mothers, households in which the main earner is unemployed will report higher levels of stress, and high QRS-F scores, will be associated with:

- The number of children living at home
- The number of, and perceived helpfulness of social support, as measured by the Family Support Scale.

### **3. Method**

#### **3.1 Design**

This study aims to identify the factors influencing the experience of stress in mothers of children with learning disabilities. These factors include, those associated with characteristics of the child, their mother and the environment, and will be compared to a control group of mothers of children for whom there are no developmental concerns.

This study has chosen to look at stress in mothers specifically, because, as a result of the limitations imposed upon this study, this subject group has been chosen due to their accessibility. Secondly, mothers are more likely to be responsible for the care of their child with learning disabilities (Parker & Lawton, 1910), thirdly, gender differences have been found to exist between mothers and fathers and their experience of stress associated with bringing up their child with learning disabilities (Beckman, 1991), and finally, historically, studies have examined maternal reactions to their learning disabled child and, as such, this enables comparison of findings to previous studies.

This study is a questionnaire design. Participants were asked to attend a 30-minute semi-structured interview during which time five questionnaires were completed. The semi-structured interview was designed to overcome potential literacy problems in the two groups, and to promote an informal atmosphere and an opportunity for participants to ask questions.

### **3.2 Procedure**

All participants received an information sheet outlining the aims of the project and inviting them to become involved.

Mothers of children with developmental disabilities, were accessed through a special needs clinic, run by the local Consultant Paediatrician. The Paediatrician gave each mother, with a child between the ages of 5 and 16, an information sheet outlining the project, and inviting them to become involved (Appendix 1), during their routine appointment. If the mother was interested, the Paediatrician then introduced them to the researcher who was available to answer questions and arrange an appropriate time to complete the questionnaires if they consented to do so.

The control group were randomly selected from a GP database of mothers of children between the ages of 5 & 16 registered at their practice. In addition, and as a result of the poor response rate from the randomly selected group, local health care professionals and their friends, with children between the ages of 5 & 16, were invited to become involved. The control group received an information sheet and an invitation to become involved (Appendix 2) by post and were asked to contact the researcher by telephone if they had any questions regarding the project.

For those willing to take part, a consent form was completed (Appendix 3) and their address was noted if they were interested in receiving a summary of the results of the project on

completion. This consent form was kept separate from their responses in order to maintain confidentiality.

Having consented to take part in the project the interview either took place immediately, as was the case for most of the research group, or a home visit was arranged. All participants were asked questions relating to, the demographics of their family; the presence of challenging behaviour in their child; their experience of low mood; their experience of stress in relation to their child and the social support networks they used to help them cope on a day to day basis.

### 3.3 Participants

This study was conducted with mothers of children with learning disabilities (research group) and a control group of mothers for whom there were no concerns about their child's development (control group). Participants were all living in the Scottish Borders, an area with a population of approximately 106 000.

#### Research Group

The exclusion criteria for the research group included:

- Mothers of children with learning disabilities under the age of 5 years
- Mothers with a history of severe mental illness
- Mothers with a history of drug and / or alcohol abuse

Of the 41 mothers informed of the project through the Paediatrician, 30 consented to take part, giving a response rate of 73.2 per cent. The demographics of this group are presented in table 3.3.1 overleaf<sup>1</sup>:

---

<sup>1</sup> Demographic information was not available for those who declined to take part



Table 3.3.1

Research Group Demographics

|                                       |                              | Total Frequency | Percentage of Total Group |
|---------------------------------------|------------------------------|-----------------|---------------------------|
| <b>Marital Status</b>                 | Married                      | 24              | 80                        |
|                                       | Single                       | 6               | 20                        |
| <b>Occupation of Main Earner</b>      | Unemployed                   | 10              | 33.3                      |
|                                       | Manual worker                | 8               | 26.6                      |
|                                       | Professional                 | 12              | 40                        |
| <b>No. of Children living at Home</b> | 1-2                          | 17              | 56.6                      |
|                                       | 3-4                          | 12              | 40                        |
|                                       | 5+                           | 1               | 3.3                       |
| <b>Child's Diagnosis</b>              | Developmental Delay          | 11              | 36.7                      |
|                                       | Autism                       | 6               | 20                        |
|                                       | Cerebral Palsy               | 5               | 16.7                      |
|                                       | ADHD                         | 3               | 10                        |
|                                       | Specific Learning Difficulty | 2               | 6.7                       |
|                                       | Down's Syndrome              | 1               | 3.3                       |
|                                       | Noonan's Syndrome            | 1               | 3.3                       |
|                                       | Fragile X                    | 1               | 3.3                       |
|                                       | 5-7                          | 11              | 36.6                      |
|                                       | 8-10                         | 8               | 26.6                      |
| <b>Child's Age</b>                    | 11-13                        | 9               | 30                        |
|                                       | 14-16                        | 2               | 6.6                       |
|                                       | 17-20                        | 1               | 3.3                       |
| <b>Child's Gender</b>                 | Male                         | 20              | 66.7                      |
|                                       | Female                       | 10              | 33.3                      |
| <b>Sensory Impairments?</b>           | Yes                          | 11              | 36.7                      |
|                                       | No                           | 19              | 63.3                      |
| <b>Physical Impairments?</b>          | Yes                          | 11              | 36.7                      |
|                                       | No                           | 19              | 63.3                      |

Control Group

The control group was randomly selected from a local GP database of mothers of children between the ages of 5 and 16 living in the Scottish Borders. In addition, questionnaires were



randomly distributed amongst local health care practitioners and their friends. The following exclusion criteria for this group included:

- Children with a developmental delay
- Children with mental health problems
- Children with chronic health problems

A total of 60 information sheets and invitations to become involved in the project were sent by post and 40 were handed to local health care practitioners. The control group were asked to contact the researcher if they were interested in becoming involved in the project, and an arrangement was then made to visit them at home to complete the questionnaires.

Of the 60 mothers informed of the project by post, 7 consented to take part, giving a response rate of 11.6 per cent. Of the 30 handed to local health care practitioners and their friends, 18 responded, giving a response rate of 60 per cent. A total of 100 questionnaires were distributed to controls, giving an overall response rate of 25 per cent.

Group 2 consisted of 25 mothers of children for whom there were no concerns about their development. The demographics of this group are presented in table 3.3.2 overleaf. Research group data are presented in brackets so direct comparisons can be made.

Table 3.3.2

Control Group and Research Group Demographics

|                                  |              | Frequency | Percentage of Total |
|----------------------------------|--------------|-----------|---------------------|
| <b>Marital Status</b>            | Married      | 19 (24)   | 76 (80)             |
|                                  | Single       | 6 (6)     | 24 (20)             |
| <b>Occupation of Main Earner</b> | Unemployed   | 3 (10)    | 12 (33.3)           |
|                                  | Manual       | 6 (8)     | 24 (26.6)           |
|                                  | Professional | 16 (12)   | 64 (40)             |
| <b>No. of Children at Home</b>   | 1-2          | 20 (17)   | 80 (56.6)           |
|                                  | 3-4          | 5 (12)    | 20 (40)             |
|                                  | 5+           | 0 (1)     | 0 (3.3)             |

**Matched Sample**

In terms of having obtained a matched sample, two variables were identified, due to their potential effect upon stress. Marital status (Beckman, 1984) and occupation of the main earner (Barber et al 1988; Quine & Pahl, 1985).

In terms of demographics, marital status for both groups, appear to be matched. A t-test was conducted on the total sample and there were no significant differences found between mean scores for married or single mothers on stress and depression scores, measured by the QRS-F and the BDI respectively. Therefore, it can be assumed that for the total sample marital status does not have a significant impact upon stress and depression scores.

Looking at descriptive data alone, there are proportionately more research participants with unemployment status than controls and proportionately less research participants with professional status. Due to the presence of one dependant variable with three factor levels (unemployed, manual worker, professional), a univariate analysis of variance conducted upon the total sample, found no significant difference in stress and depression, as measured by the

QRS-F and the BDI respectively, for each category of employment. This suggests that, although the groups appear to be unmatched in terms of occupation of the main earner, in this sample, the occupation of the main earner had no significant impact upon stress and depression experienced by the mother. Despite this, however, the occupation of the main earner was used as a covariate where possible throughout the analyses to control for any potential effect it may have upon results.

In conclusion, therefore, the two samples are matched in terms of marital status but not in terms of the occupation of the main earner. Further statistical analysis shows that, in terms of the total sample, this variable has no significant effect upon stress and depression scores. However, due to the evidence that socio-economic status can have a significant impact upon stress levels in mothers of children with learning disabilities (Barber et al, 1988; Quine & Pahl, 1985), the occupation of the main earner was entered into further analysis as a covariate to control for its potential impact upon stress scores.

### 3.4 Measures

All participants were guided through 5 questionnaires during the semi-structured interview

#### 3.4.1 Demographic Instrument

Participants were asked to complete a one-page demographic questionnaire (Appendix 4). All participants were asked questions relating to their current family situation. In addition mothers of children with learning disabilities were asked questions specifically about their child and whether they felt they were adequately supported.

#### **Family Situation: (All participants)**

The information obtained in relation to their family situation included, their marital status; the occupation of the main earner living at home; the number of children living at home<sup>2</sup>.

The next question was a forced choice question asking participants to indicate if their child had a learning disability. The control group (mothers of children for whom there were no concerns about their development) were asked to indicate “NO” and move onto the next page. Mothers of children with developmental disabilities were asked to continue answering the questions about their child and the adequacy of their support networks.

---

<sup>2</sup> This was asked for information only and was not entered into further statistical analyses

### **Child with Learning Disabilities: (Research group only)**

The information obtained in relation to the child with learning disabilities included, specification of diagnosis (if available); the age of the child<sup>3</sup>; its gender<sup>4</sup> and whether their child had any sensory or physical impairments.

### **Adequacy of Support Networks: (Research group only)**

The information obtained in relation to the adequacy of their support networks included, identifying, whether the mother felt she received adequate support and if not, what additional support did she require. This data was then collated to provide evidence of the adequacy of supports for mothers of children with learning disabilities and the areas they felt they required additional support. Scoring criteria for the demographic questionnaire can be found in appendix nine.

#### **3.4.2 *Challenging Behaviour Questionnaire***

In the challenging behaviour questionnaire (Appendix 5), both research and control participants were asked to indicate, by circling YES or NO, whether their child displayed any challenging behaviour. They were then asked to indicate, by placing a tick in the corresponding box, which forms of challenging behaviour their child displayed. If their child's behaviour was not indicated on the list, they were asked to give details of their child's behaviour in the space provided. The forms of challenging behaviours that were included in this questionnaire were based upon those categories highlighted by Hastings and Remington (1994) and included, violence and aggression; self injurious behaviour; destructive behaviour; disruptive behaviour; stereotypy and passive behaviour.

---

<sup>3</sup> This was obtained for information only and no further analysis was conducted upon this variable

<sup>4</sup> This was obtained for information only and no further analysis was conducted upon this variable

### 3.4.3 Beck Depression Inventory

The Beck Depression Inventory (Beck et al, 1996), (Appendix 6), was used to measure depression in both the research and control group. This instrument consists of 21 symptoms or attitudes commonly seen in patients suffering from depression, for example, sadness, pessimism, loss of pleasure, guilt and suicidal thoughts and wishes. The participant's responses were rated from 0 to 3 in intensity. For example, when rating sadness, respondents were asked to indicate the intensity of their sadness between

0 = "I do not feel sad,"

3 = I am so sad or unhappy that I can't stand it.

It is argued that the term "depression" should not be used from a single administration of the BDI and that a full clinical interview should accompany it to make an accurate diagnosis. The BDI is a measure of the severity of depression and as such, table 3.4.1 outlines the cut-off points used when interpreting the results obtained in this study:

Table 3.4.1

#### Cut-off scores on the BDI

| <b>BDI score</b> | <b><i>Risk</i></b> |
|------------------|--------------------|
| 0-13             | Minimal Severity   |
| 14-19            | Mild Severity      |
| 20-28            | Moderate Severity  |
| 29-63            | Severe Severity    |

In large samples, the mean BDI score usually falls between 4 and 6, with women scoring approximately two points higher than men (Beck et al 1996).

#### 3.4.4 The Short-Form of the Questionnaire on Resources and Stress (QRS-F)

Both the research and control group were asked to complete the QRS-F (Friedrich, Greenberg & Crnic, 1983) (Appendix 7). The QRS-F was developed in 1983 from Holroyd's (1974) much longer Questionnaire on Resources and Stress (285 items). The QRS-F consists of 52 items and requires respondents to indicate a "true" or "false" answer in response to each item. It is designed to measure the impact of a developmentally delayed, or chronically ill child on other family members, although it has also been used in research comparing stress in families with and without children with learning disabilities (Dyson, 1993). The QRS-F asks respondents about their feelings about a child in their family. Participants must think of a child in their family when responding to the statements, for example, "\_\_\_\_\_ doesn't communicate with others of his/her age group." The 52 items converge on four factors, see table 3.4.2 below:

Table 3.4.2

Four factors of the QRS-F

| Factor Number | Number of Items | Factor                     |
|---------------|-----------------|----------------------------|
| 1             | 20 items        | Parent and Family Problems |
| 2             | 11 items        | Parental Pessimism         |
| 3             | 15 items        | Child Characteristics      |
| 4             | 6 items         | Physical Incapacitation    |

This shortened form of the original Holroyd (1974) scales has been widely used in family research and has reasonable alpha reliability, factor structure and construct validity (Dyson, 1989, Flynt & Wood, 1989 & Scott et al, 1989).

3.4.5 The Family Support Scale (FSS)

The Family Support Scale (Appendix 8), was developed by Dunst, Jenkins and Trivette (1984), to measure the degree to which different sources of support were helpful to families. It asks respondents to rate the helpfulness of 18 sources of support over the last 3-6 months on a 5-point likert scale ranging from “not helpful at all” (1) to “extremely helpful” (5), and allows them to indicate two further sources of support if they are not covered in the original list. The FSS provides information to the researcher including, the number of supports available to the individual, the sources of these supports and their helpfulness. The sources of support can be considered as five sub-scales indicated in table 3.4.3 below:

Table 3.4.3  
Sources of support indicated by the FSS

| Sources of Support    | Included in this definition  |
|-----------------------|--|
| Partner / Spouse      | Partner,<br>Partner's parents<br>Partner's relatives   |
| Informal Kinship      | Friends<br>Partner's friends<br>Own children<br>Other parents<br>Place of worship                          |
| Formal Kinship        | Own parents<br>Own relatives   |
| Social Organisations  | Co-workers<br>Parent groups<br>Social groups / clubs<br>Professional helpers                               |
| Professional Services | Family / child's doctor<br>Early<br>intervention programme<br>School / Day centre<br>Professional agencies |

The scale was initially developed to study the mediating effects of social support on how parents cope with the demands of rearing a child with disabilities. This tool can be used in both clinical and research settings to access a range of information about family social networks (Dunst and



Trivette, 1990). The FSS has demonstrated acceptable levels of discriminant and construct validity (Dunst et al, 1984).

### **3.5 Statistical Analyses**

#### **3.5.1 Statistical Analysis**

All analyses were conducted using version 10 of the Statistical Package for the Social Sciences (SPSS)

#### **3.5.2 Hypothesis 1**

Mothers of children with learning disabilities will experience more stress, measured by the QRS-F (Appendix 7), than mothers of children without learning disabilities.

A t-test was conducted to compare scores obtained on the QRS-F between the research group and the control group. In addition, due to the presence of more than one dependant variable, a 2 x 4 multivariate analysis of covariance was conducted, with “occupation of the main earner” as the covariate, to identify any significant differences between the two groups on the four factors of the QRS-F, while removing the variance that can be attributed to the “occupation of the main earner.”

#### **3.5.3 Hypothesis 2**

##### **Child Characteristics**

Mothers of children with learning disabilities will report more challenging behaviour displayed by their children, as measured by the informal challenging behaviour questionnaire (Appendix 5), than mothers of children without learning disabilities

All mothers were asked to indicate if their child displayed challenging behaviour by circling yes or no. Due to the categorical nature of the responses made to this question, therefore, a 2 x 2 chi-square analysis was conducted to compare the research group and the control group on their responses to this question. In addition, 2 x 2 chi-square analyses were used to identify differences between the research and control group in terms of the type of challenging behaviour their child displayed. Finally, a t-test compared the total number of challenging behaviours indicated by both groups.

a) Within the group of mothers with children with learning disabilities, high QRS-F scores will be associated with:

- Presence of sensory and physical impairments
- Presence of challenging behaviour and the number of challenging behaviours indicated

Due to the dichotomous, yes / no response to the question, does your child have sensory or physical impairments, a point bi-serial correlation was conducted to identify the association between responses to this question and QRS-F scores. A point bi-serial correlation was also conducted to identify the relationship between the presence of challenging behaviour and QRS-F scores and a Pearson's correlation was conducted to identify the relationship between the number of challenging behaviours indicated and QRS-F scores.

#### 3.5.4 Hypothesis 3

##### **Maternal Characteristics**

Mothers of children with learning disabilities will be at higher risk of depression, as measured by the BDI (Appendix 6), than mothers of children without learning disabilities

A 2 x 4 chi square analysis was conducted to identify if there was a significant difference between groups in terms of the category of risk of depression into which they fell. In addition, a t-test was conducted to identify differences between the research group and the control group on total BDI scores.

a) Within the group of mothers with children with learning disabilities, high QRS-F scores will be associated with:

- Presence of depression as measured by the BDI

A pearson's correlation was used to identify if there was a relationship between QRS-F scores and BDI scores

#### 3.5.5 Hypothesis 4

##### **Environmental Characteristics**

Mothers of children with learning disabilities will use less social support networks, as measured by the Family Support Scale (Appendix 8), although they will use more professional services, than mothers of children without learning disabilities.

A t-test was conducted to identify if there was a difference between groups in terms of the total number of supports they used. In addition, due to the presence of more than one dependent variable, a 2 x 5 multivariate ANOVA was conducted to identify if there was a difference between groups on the number of supports they had in each of the five factor areas.

a) There will be no difference between the helpfulness of supports indicated by mothers of children with learning disabilities and mothers of children without learning disabilities

Participants were asked to indicate on a scale of 0 to 5 how helpful they found each source of support. Aitken (1969) recommended using parametric methods with likert scales as long as the data formed a normal distribution or was transformed to achieve a normal distribution. However, Howell (1997) reported that parametric tests are sufficiently robust to violations of their assumptions. Therefore, in this case, A t-test was used to identify the difference between groups on the perceived helpfulness of their support network as a whole. In addition, due to the presence of more than one dependent variable, a 2 x 5 multivariate ANOVA was conducted to identify differences between groups in terms of the helpfulness of supports in each of the five factor areas.

b) There will not be an association between the number of supports received and their perceived helpfulness

A pearson's correlation was used to identify if there was a significant relationship between the number of supports and their perceived helpfulness.

c) Mothers of children with learning disabilities will report an insufficient degree of support in general

Descriptive statistics were used to present this data

d) Within the group of mothers with children with learning disabilities, single mothers will report more stress than married mothers,

A t-test was used to identify differences in QRS-F scores between married and single mothers

Households in which the main earner is unemployed will report higher levels of stress,

Due to the presence of one dependant variable with three levels a univariate ANOVA was conducted to identify differences in QRS-F scores between unemployed, manual workers and professionals.

High QRS-F scores, will be associated with:

- The number of children living at home

Due to the skewed nature of the data, a spearman's correlation was conducted to identify the relationship between the number of children living at home and QRS-F scores

- The number of, and perceived helpfulness of social support, as measured by the Family Support Scale

Pearson's correlation was conducted to identify the relationship between the number of supports and the perceived helpfulness of these supports and QRS-F scores.

### **3.6 Power Analysis**

Based on the literature (Dyson, 1997; Hodapp et al. 1997; Weiss 2002), it was assumed that a significant difference would be found between groups of between 30 and 40 on the measures utilised in this study, therefore a large effect size would be achieved. Based on Cohen's (1992) estimate of sample size, setting power at 0.8 and alpha at 0.05, t-test analysis would require that  $N = 26$ . For multivariate analyses, with 5 dependant variables, and univariate analyses, with only one dependant variable, and assuming a large effect size, setting power at 0.8 and alpha at 0.05,  $N = 16$  &  $N = 26$  respectively. For correlational analyses and assuming a large effect size, setting power at 0.8 and alpha at 0.05,  $N = 28$ . Finally, for non-parametric chi-square analyses and assuming a large effect size, setting power at 0.8 and alpha at 0.05,  $N = 26$ . Therefore recruitment of between 25 and 30 subjects would provide a reasonable chance of rejecting the null hypothesis.

### **3.7 Ethical Approval**

Permission to conduct this study was sought through a local ethics committee and was granted.

## 4. Results

### 4.1 Hypothesis 1

Mothers of children with learning disabilities will experience more stress, measured by the QRS-F (Appendix 7), than mothers of children without learning disabilities.

After the removal of one outlier from the control group data, QRS-F scores were normally distributed for both groups (Appendix 10). Due to the normal distribution of QRS-F scores for both groups, and the interval nature of the data, parametric assumptions were met. A two-tailed t-test found a significant difference between the research and control group on QRS-F scores ( $t=10.869$ ,  $df = 52$ ,  $p<0.001$ )<sup>5</sup>. In addition, appealing to robustness and due to the presence of more than one dependant variable, a multivariate analysis of covariance was conducted to determine differences between the two groups in terms of the four factors of the QRS-F. A 2 x 4 analysis was conducted, using the occupation of the main earner as a covariate due to its potential effect upon stress scores. This analysis identified a significant difference between the research and control groups on all factors of the QRS-F, including family problems,  $F(1,51)=35.983$ ,  $p<0.001$ ; pessimism,  $F(1,51)=111.563$ ,  $p<0.001$ ; child characteristics,  $F(1,51)=112.117$ ,  $p<0.001$  and physical incapacity,  $F(1,51)=24.362$ ,  $p<0.001$ .

---

<sup>5</sup> Without removing this outlier and conducting non-parametric statistics, due to the skewed nature of the control group data, a significant result ( $u = 22.500$ ,  $z = -5.974$ ,  $p<0.001$ ) was still obtained



## 4.2 **Hypothesis 2**

### Child Characteristics

Mothers of children with learning disabilities will report more challenging behaviour displayed by their children, as measured by the informal challenging behaviour questionnaire (Appendix 5), than mothers of children without learning disabilities

In order to identify what influence the presence of challenging behaviour may have upon stress experienced by mothers of children with learning disabilities, it is important to identify whether in fact mothers of children with learning disabilities are more likely to report the presence of challenging behaviour in their child in this sample. Table H2.1 overleaf illustrates the number of respondents in both groups who reported that their child displayed challenging behaviour. In addition, the table highlights the form of challenging behaviour their child displayed. (Percentages of each sample are shown in brackets).

Table H2.1 Challenging Behaviour reported by the research group and the control group

Research Group (n = 30)  
Control Group (n = 25)

| CB? | Viol/Agg        | SIB             | Destruct        | Disrupt         | Stereoty        | Passive         | Other           |
|-----|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Yes | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> |
|     | 23(76.7)        | 16(53.3)        | 8(26.7)         | 10(33.3)        | 16(53.3)        | 7(23.3)         | 10(33.3)        |
|     | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> |
|     | 5 (20)          | 2 (8)           | 0 (0)           | 1 (4)           | 2 (8)           | 0 (0)           | 1 (4)           |
| No  | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> |
|     | 7 (23.3)        | 14 (46.7)       | 22 (73.3)       | 20 (66.7)       | 14 (46.7)       | 23 (76.7)       | 20 (66.7)       |
|     | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> |
|     | 20 (80)         | 23 (92)         | 25 (100)        | 24 (96)         | 23 (92)         | 25 (100)        | 24 (96)         |

Key: CB? Presence of Challenging Behaviour  
Viol/Agg Violence and aggression displayed  
SIB Self injurious behaviour displayed  
Destruct Destructive behaviour displayed  
Disrupt Disruptive behaviour displayed  
Stereoty Stereotyped behaviour displayed  
Passive Overly passive behaviour displayed  
Other Other behaviours displayed, not otherwise mentioned

The table above illustrates that, in terms of descriptive data, mothers of children with learning disabilities report more challenging behaviour than mothers of children for whom there are no concerns about their child’s development. This is also the case across all forms of challenging behaviour. In addition, across both groups, mothers are more likely to report that their child displays violence and aggression and disruptive behaviour than any other form of challenging behaviour.

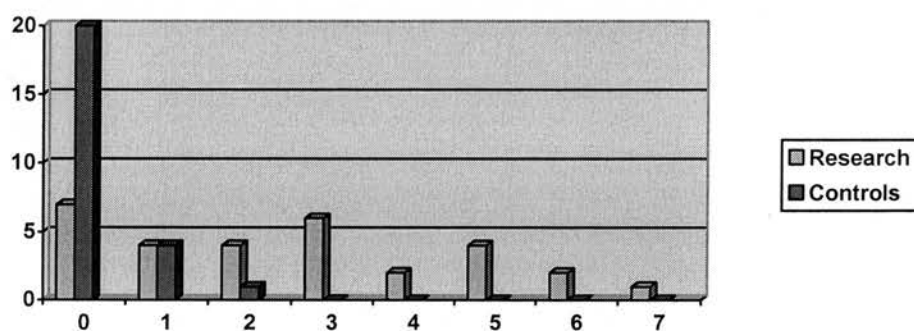
Mothers of both groups were asked to indicate whether their child displayed challenging behaviour by circling yes or no. Due to the categorical nature of this data therefore, a chi-square analysis was conducted to identify whether the differences between groups were statistically significant. A 2 x 2 chi-square analysis revealed that mothers of children with learning

disabilities were significantly more likely to report that their child displayed challenging behaviour (chi-square=17.521, df=1,  $p<0.05$ ). In addition, mothers of children with learning disabilities were more likely to report that their child displayed all types of challenging behaviour including, violence and aggression (chi-square=12.729, df=1,  $p<0.05$ ); self injurious behaviour (chi-square=7.801, df=1,  $p<0.05$ ); destructive behaviour (chi-square=7.333, df=1,  $p<0.05$ ); disruptive behaviour (chi-square=12.729, df=1,  $p<0.05$ ); stereotyped behaviour (chi-square=6.684, df=1,  $p<0.05$ ); overly passive behaviour (chi-square=7.333, df=1,  $p<0.05$ ); and other challenging behaviours (chi-square=8.967, df=1,  $p<0.05$ ).

Graph H2.1 below, illustrates the number of challenging behaviours reported by each group. Not only are mothers of children with learning disabilities more likely to report the presence of challenging behaviour in their child, but, it appears that their child is likely to display *more* challenging behaviours than mothers of children without learning disabilities.

Graph H2.1

The Number of Challenging Behaviours Reported by Both Groups



In addition, table H2.2 below illustrates the mean number and standard deviation of challenging behaviours reported by mothers in both groups.

Table H2.2

Mean Number of challenging behaviours reported by mothers in both groups

|  | N               | Minimum         | Maximum         | Mean            | Std. Deviation  |
|--|-----------------|-----------------|-----------------|-----------------|-----------------|
| Number of challenging behaviours displayed | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> | <u>Research</u> |
|  | 30              | .00             | 7.00            | 2.56            | 2.11            |
|  | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> | <u>Controls</u> |
|  | 25              | .00             | 2.00            | .2400           | .5228           |

In order to identify whether there is a statistical significance between the *number* of challenging behaviours reported by both groups, a Mann-Whitney U analysis was conducted due to the skewed nature of the control group data. This analysis found a significant difference between the research and control group in terms of the number of challenging behaviours reported ( $u = 119.000$ ,  $z = -4.622$ ,  $p < 0.05$ ).

4.2.1 *Hypothesis 2A*

Within the group of mothers with children with learning disabilities, high QRS-F scores will be associated with:

- Presence of sensory and physical impairments
- Presence of challenging behaviour and the number of challenging behaviours indicated

Due to the categorical nature of participant’s responses to the question, does your child have any sensory impairments, a point-biserial correlation was used to determine if there was a significant association between responses to this question and QRS-F scores. No significant association was found between the presence of sensory difficulties and QRS-F scores.

A similar analysis was conducted to reveal any associations between the presence of physical impairments and QRS-F scores. No significant association was found.

A third analysis was conducted to identify whether there was any association between the presence of *both* sensory impairments and physical impairments and QRS-F scores. Again there was no significant association found.

In terms of the association between QRS-F scores and the presence of challenging behaviour, a point- biserial correlation found no significant association between these variables. However, a pearson's correlation found a significant relationship between the *number* of challenging behaviours exhibited by the child and the level of stress experienced by the mother as measured by the QRS-F ( $\rho = .359, p < 0.05$ ).

4.3 Hypothesis 3

Maternal Characteristics

Mothers of children with learning disabilities will be score higher on the BDI (Appendix 6), than mothers of children without learning disabilities

Table H3.1 outlines the frequency of BDI scores for both groups, falling within the minimal, mild, moderate and severely depressed ranges.

Table H3.1

The Frequency of Data in Terms of Severity of Depression

|               | Minimal<br>severity | Mild<br>severity | Moderate<br>severity | Severe<br>severity |
|---------------|---------------------|------------------|----------------------|--------------------|
| ResearchGroup | 13 (43.3%)          | 2 (6.7%)         | 7 (23.3%)            | 8 (26.7%)          |
| Control Group | 23 (74.2%)          | 1 (3.2%)         | 1 (3.2%)             | 0                  |

When comparing differences between groups in terms of the category of depression into which they fell, a non-parametric chi-square analysis was conducted. Due to expected frequencies less than five, the categories mild, moderate and severe were combined. A 2 x 2 chi-square analysis revealed a significant difference between groups in terms of the category of depression into which they fell (chi-square = 17.180, df=1, p<0.001), suggesting that mothers of children with learning disabilities were significantly more likely to fall into the mild, moderate or severe categories of depression than mothers of children without learning disabilities

In comparing total BDI scores across both groups, after the removal of the two outliers from the control group data (Appendix 11), BDI scores were normally distributed for both groups. Due to

the normal distribution for both groups, and the interval nature of the data, parametric assumptions were met. A two-tailed t-test was conducted and a significant difference was found between BDI scores for the research group and the control group ( $t = 6.062$ ,  $df = 51$ ,  $p < 0.01$ )<sup>6</sup>, suggesting that mothers of children with learning disabilities were likely to score higher on the BDI than mothers of children without learning disabilities.

#### 4.3.1 *Hypothesis 3A*

Within the group of mothers with children with learning disabilities, high QRS-F scores will be associated with

- Presence of depression as measured by the BDI

Within the research group, pearson's correlation found a positive correlation between QRS-F scores and BDI scores,  $r = .281$ . However, this association was not statistically significant.

---

<sup>6</sup> Without removing these outliers, and conducting non-parametric statistics due to the skewed nature of the control group data, a significant result ( $u = 73.000$ ,  $z = -5.114$ ,  $p < 0.001$ ) was still obtained.

#### 4.4 Hypothesis 4

##### Environmental Characteristics

Mothers of children with learning disabilities will use less social support networks, as measured by the Family Support Scale (Appendix 8), although they will use more professional services, than mothers of children without learning disabilities

##### Sources of Support

Table H4.1 below illustrates the number of sources of support in each area, as indicated from responses on the FSS. This was calculated by adding the number of supports indicated in each area. The cumulative number of supports indicated in each area has been collated in table H4.1 below.

Table H4.1

The Number of Sources of Support Indicated by each group on the FSS

|  | N              | Minimum | Maximum | Mean  | Std. Deviation |
|--|----------------|---------|---------|-------|----------------|
| Total Number of Supports<br>(max = 18) | Research<br>30 | 6.00    | 16.00   | 11.03 | 2.47           |
|  | Controls<br>25 | 1.00    | 19.00   | 10.64 | 3.34           |
| Partner<br>(max = 3)                   | Research<br>30 | .00     | 3.00    | 1.86  | 1.07           |
|  | Control<br>25  | .00     | 3.00    | 2.28  | .89            |
| Informal kin<br>(max = 5)              | Research<br>30 | 1.00    | 4.00    | 2.93  | .98            |
|  | Control<br>25  | .00     | 5.00    | 3.44  | 1.26           |
| Formal kin<br>(max = 2)                | Research<br>30 | .00     | 2.00    | 1.36  | .80            |
|  | Control<br>25  | .00     | 2.00    | 1.72  | .61            |
| Social organisations<br>(max = 4)      | Research<br>30 | .00     | 4.00    | 1.63  | .96            |
|  | Control<br>25  | .00     | 4.00    | 1.64  | 1.11           |
| Professional services<br>(max = 4)     | Research<br>30 | 1.00    | 3.00    | 2.76  | .50            |
|  | Control<br>25  | .00     | 3.00    | 1.16  | .80            |



Table H4.1 illustrates that both research and control subjects identified that their largest number of supports came from informal kin (indicated in bold), followed closely by professional services for the research group and partner related sources by the control group.

In terms of whether there was a statistical significance between the research and control groups and the number of supports they indicated on the FSS, distribution of both groups of data revealed 2 outliers in the control group data (Appendix 12). After the removal of both outliers from the control group data, both groups met assumptions for parametric statistics. A t-test revealed no significant difference between the total number of supports indicated by each group<sup>7</sup>, suggesting that mothers of children with learning disabilities do not use less social supports than mothers of children without learning disabilities.

When comparing groups in terms of the number of supports in each of the five factor areas, due to the presence of more than one dependant variable and appealing to robustness (Howell, 1997), a 2 x 5 multivariate ANOVA was conducted. No significant differences were found between groups in terms of the number of partner related supports, informal kin supports, formal kin supports and social supports. However, a significant difference did exist between groups in terms of the number of professional services used,  $F(1,53)=82.090$ ,  $p<0.001$ . As predicted, therefore, mothers of children with learning disabilities were likely to have more supports from professional services than mothers of children without learning disabilities.

---

<sup>7</sup> Without removing these outliers and conducting non-parametric statistics due to the skewed nature of the control group data, a non-significant result was also produced.

#### 4.4.1 Hypothesis 4A

There will be no difference between the helpfulness of supports indicated by mothers of children with learning disabilities and mothers of children without learning disabilities

##### Helpfulness of support

Table H4.2 below indicates how helpful respondents found each area of support. This was calculated by identifying how many sources of support they had identified in each area (n), totaling the helpfulness (h) indicated on a likert scale of 1-5 in each area, and dividing this number by (n), giving an average helpfulness rating for each support area. The cumulative average is therefore presented in table H4.2:

Table H4.2

Total helpfulness of each area of support rated by each group on the FSS

|                                 | N                         | Minimum       | Maximum        | Mean           | Std. Deviation |
|---------------------------------|---------------------------|---------------|----------------|----------------|----------------|
| Total Helpfulness Score         | Research 30<br>Control 25 | 15.00<br>2.00 | 58.00<br>56.00 | 32.03<br>28.52 | 9.88<br>11.02  |
| Partner (max = 5)               | Research 30<br>Control 25 | .00<br>.00    | 5.00<br>5.00   | 3.02<br>2.92   | 1.43<br>1.18   |
| Informal kin (max = 5)          | Research 30<br>Control 25 | 1.25<br>.00   | 5.00<br>4.00   | 2.89<br>2.39   | 1.05<br>.81    |
| Formal kin (max = 5)            | Research 30<br>Control 25 | .00<br>.00    | 5.00<br>5.00   | 2.28<br>3.00   | 1.66<br>1.27   |
| Social organisations (max = 5)  | Research 30<br>Control 25 | .00<br>.00    | 5.00<br>5.00   | 2.64<br>2.52   | 1.34<br>1.47   |
| Professional services (max = 5) | Research 30<br>Control 25 | 1.30<br>.00   | 5.00<br>5.00   | 3.16<br>2.36   | .74<br>1.36    |

Interestingly research participants indicated that professional services were most helpful in supporting their child (indicated in bold) even although they indicated that cumulatively they had more supports in informal kin. Controls indicated that formal kin provided the most helpful support, although they too cumulatively identified that they received the largest number of supports from informal kin. This supports the notion that the perceived helpfulness of the support received is not necessarily associated with the number of supports received.

Helpfulness was rated on a 6 point likert scale from 0 = not available to 5 = extremely helpful. The distribution of total helpfulness scores are presented in Appendix 13. Appealing to Aitken (1969) who supports the notion that parametric statistical analysis can be used when analysing likert scales, parametric analyses were used to identify differences in total helpfulness scores and on reported helpfulness of each of the five factor scores. Due to the normal distribution of data sets for both groups, a t-test was conducted. As predicted, no significant difference was found between groups on total helpfulness scores. Therefore, there was no difference between groups in terms of their perception of the helpfulness of the supports they received

When comparing the difference between groups on helpfulness ratings in each of the 5 factor areas, due to the presence of more than one dependant variable and appealing to robustness (Howell, 1997), a 2 x 5 multivariate ANOVA was conducted. No significant differences were found between groups in terms of their perceived helpfulness of partner related supports, informal kin supports, formal kin supports or social organisations. However significant differences were found between groups in terms of how helpful they perceived professional services  $F(1,53)=7.819$ ,  $p<0.001$ , suggesting that mothers of children with learning disabilities found professional services more helpful than mothers of children without learning disabilities.

#### 4.4.2 *Hypothesis 4B*

There will not be an association between the number of supports received and their perceived helpfulness

In terms of the total sample, to identify whether there was any association between the number of supports indicated in each area on the FSS and the helpfulness of these supports, a pearson's correlation found a significant correlation between the total number of supports indicated and the total helpfulness rating ( $r = .641$ ,  $p < 0.001$ ), suggesting that for this sample, there was a significant association between the total number of supports used and their perceived helpfulness overall, i.e. the larger the number of supports indicated, the more helpful these supports were perceived.

However for each area of support, pearson's correlation indicated no significant correlation between the number of partner related supports ( $r = .090$ ), informal supports ( $r = -0.57$ ), social organisational supports ( $r = .199$ ) and their helpfulness. However, a significant correlation was identified between the number of supports from formal kin and their helpfulness ( $r = .650$ ,  $p < 0.001$ ) and the number of supports from professional services and their helpfulness ( $r = .465$ ,  $p < 0.001$ ). This suggests that when the group is taken as a whole sample, they indicated that as the number of supports in the formal kin category (mother's parents, and relatives) and the number of supports in the professional services category (including GPs, paediatricians and teachers) increased, the perceived helpfulness of these supports increased also.

For the research group only, pearson's correlation found a significant positive correlation between the total number of supports indicated and their total helpfulness rating ( $r = .647$ ,

$p<0.01$ ). This suggests that for mothers of children with learning disabilities, as the total number of supports available to them increases, so too does their perceived helpfulness.

Looking at each of the five factor areas measured by the FSS, a significant positive correlation was found between the number of formal kin supports (the mother's parents and relatives) and their helpfulness ( $r = .676$ ,  $p<0.01$ ) for mothers of children with learning disabilities. No other significant associations were found between the number of supports in each of the remaining factors areas and their helpfulness.

#### 4.4.3 Hypothesis 4C

Mothers of children with learning disabilities will report an insufficient degree of support in general

#### Demographics from informal questionnaire

Within the research group, 66.7 per cent felt that they did not receive adequate support. In terms of support required by this group, table 4.3 below illustrates their responses

Table H4.3

Support required as indicated by mothers of children with learning disabilities

|                                    | Frequency | Percent |
|------------------------------------|-----------|---------|
| Child related professional support | 13        | 43.3    |
| Respite                            | 11        | 36.7    |
| Personal professional support      | 6         | 20      |
| Support group                      | 4         | 13.3    |
| Sibling support                    | 3         | 10      |
| Information                        | 1         | 3.3     |

#### 4.4.4 Hypothesis 4D

Within the group of mothers with children with learning disabilities, single mothers will report higher levels of stress than married mothers and households in which the main earner is unemployed will report higher levels of stress. In addition, high QRS-F scores will be associated with:

- The number of children living at home
- The number of, and perceived helpfulness of social support, as measured by the Family Support Scale

#### Marital status

A t-test analysis, to reveal differences in QRS-F scores between single and married participants, identified no significant differences in QRS-F scores between married and single mothers of children with learning disabilities.

#### Occupation of Main earner

Univariate ANOVA, conducted due to the presence of three levels within one dependent variable (unemployed, manual worker, professional), found no significant difference in QRS-F scores in terms of the occupation of the main earner as indicated by mothers of children with learning disabilities

#### The Number of Children at Home

Spearman's correlation was conducted to identify whether there was an association between the number of children living at home and total QRS-F scores. This analysis found a positive

correlation between the number of children living at home and total QRS-F scores ( $r = .160$ ) for mothers of children with learning disabilities. However, this association was not significant.

#### The Number of Supports

Pearson's correlation found a negative correlation between the number of supports indicated by mothers of children with learning disabilities and their total QRS-F scores ( $r = -0.15$ ), suggesting that as the number of social supports increase the levels of stress, as measured by the QRS-F decreases. However, this association was not significant.

#### The Helpfulness of Supports

Pearson's correlation found a significant negative correlation between helpfulness of supports and QRS-F scores for mothers of children with learning disabilities ( $r = -.349$ ,  $p \leq 0.05$ ), suggesting that high QRS-F scores are associated with perceived lack of helpfulness of social supports.

## **5. Discussion**

The results of this study will be discussed, reflecting upon the literature presented in the introduction and the clinical implications of this research. Methodological limitations and problems will also be discussed with specific emphasis on the design of this study, the sample, and the measures used. Finally conclusions will be drawn and suggestions for further research will be proposed.

### **5.1 Discussion of Results**

This study aimed to identify whether mothers of children with learning disabilities experienced more stress than mothers of children without learning disabilities. In addition, this study aimed to identify potential exacerbating and ameliorating factors that may serve to influence the mother's experience of stress, in terms of characteristics of the child, characteristics of the mother and characteristics of the environment

It was found that mothers of children with learning disabilities experience more stress, as measured by the QRS-F, than mothers of children for whom there are no concerns about their child's development. This was found to be the case on all factors measured by the QRS-F, including, family problems; child characteristics; pessimism and physical incapacity and is consistent with that found by Weiss, (2002), Baxter et al, (2000), Dyson, (1997) and Quine and Pahl, (1985). The factors, in addition to bringing up a child with learning disabilities, that may have influenced these high QRS-F scores in the group of mothers of children with learning disabilities, include, single parenthood (Beckman, 1984) and low socio-economic status (Barber



et al, 1989 & Quine & Pahl, 1985). In this study, both the research and control group were matched in terms of marital status. Due to the fact that participants were not matched in terms of the occupation of the main earner, this factor was adopted as a covariate and an analysis of covariance was adopted to remove the variance that could be attributed to the "occupation of the main earner."

The distribution of control group data on the QRS-F was highly positively skewed, however, one outlier did exist. This individual scored highly on the QRS-F in comparison to the rest of the control group. Unfortunately there was little indication from this individuals' raw data why this may have been the case, although she also scored highly on the BDI and she indicated that her child displayed challenging behaviour. It would be premature to assume that the presence of challenging behaviour alone had influenced these high scores on both the QRS-F and the BDI, however, it is likely that these factors were related in some way. Alternatively, this raises the issue that additional stressors, unrelated to her child, may have been present in this case. Although her data was removed when comparing QRS-F scores, non-parametric statistics including this individual's scores also found significant differences between groups on QRS-F scores.

Mothers of children with learning disabilities are more likely to experience stress and the stress they experience is likely to be associated with family problems, pessimism about the future, characteristics of the child and the child's physical incapacity. All of these factors have been recognised to have a significant impact upon the experience of stress for a mother of a child with learning disabilities. In terms of family problems, it has been found that adaptive family functioning and positive family relations are associated with positive maternal adjustment and a decreased sense of maternal burden (Krauss, 1993). In terms of pessimism for the future,

Deaton (1985) found that positive maternal adjustment to their child with learning disabilities, was associated with the extent to which parents adopted a day-to-day, live for the moment type approach rather than planning for the future. Feeling despondent about the future, therefore, is likely to influence scores on the pessimism factor of the QRS-F and may explain the high scores obtained on this factor for mothers of children with learning disabilities. Child characteristics have a significant impact upon stress experienced by the mother of a child with learning disabilities, especially if those characteristics are associated with challenging behaviour (Dumas, 1991 & Hodapp, 1997) and multiple impairments (Quine & Pahl, 1985). As children with learning disabilities are more likely to display challenging behaviour (Rutter, et al, 1970 & Dykens, 2000) and are more likely to have, in some cases, physical incapacities, this explains why mothers of children with learning disabilities scored significantly more highly on these two factors than mothers of children without learning disabilities.

These findings suggest that clinicians working with children with learning disabilities need to be aware that mothers of children with learning disabilities are more likely to experience stress. Also, it is important to note, that clinicians cannot assume that the stress experienced by the child's mother is directly associated with her child with learning disabilities. While the stress that mothers experience may be associated with characteristics of her child, for example challenging behaviour, she may also be experiencing stress as a result of family problems in general, internal feelings of pessimism associated with bringing up her child or indeed, there may be additional stressors present that are unrelated to her child, for example, bereavements or work related stressors.

Hypothesis two examined characteristics associated with the child that may influence the mother's experience of stress. This study confirmed that in this sample, mothers of children

with learning disabilities were more likely to report that their child displayed challenging behaviour than mothers of children without learning disabilities. This is consistent with that found by Bregman, (1991) & Dykens, (2000). The most common forms of challenging behaviour reported by mothers of children with learning disabilities were violence, aggression and disruptive behaviour, confirming that found by Hastings and Remington (1994). In addition, in terms of the number of challenging behaviours displayed, mothers of children with learning disabilities reported that their child displayed significantly more challenging behaviours than mothers of children without learning disabilities. These results, although unsurprising, are an important preliminary analysis when identifying whether the presence of challenging behaviour has a significant influence upon stress experienced by the mother of a child with learning disabilities.

Multiple impairments and challenging behaviours are linked to heightened stress in mothers of children with learning disabilities (Quine & Pahl, 1985). However, there was no significant correlation between the presence of challenging behaviour in their child and the mother's reported levels of stress. This is an interesting finding, as one would assume that the presence of challenging behaviour would lead to heightened stress in mothers of children with learning disabilities. A significant positive correlation *was* found between the *number* of challenging behaviours reported by mothers of children with learning disabilities and their scores on the QRS-F. This supports Quine and Pahl, (1985), who reported that it may not be the presence of challenging behaviours per se that has a negative impact upon the child's mother, but the multiplicity of difficulties the child exhibits. Thus, the mother of a child displaying multiple challenging behaviours is likely to experience more stress than the mother of a child displaying only one type of challenging behaviour. This aids the understanding that mothers of children with learning disabilities can feel isolated as a result of their child's behaviour (Meltzer et al,

1989), and this can lead to heightened stress as a result of lack of support (Quine & Pahl, 1985) and low mood.

This study found no significant correlation between the presence of sensory and physical impairments and levels of stress reported by the child's mother. It is important to note, however, that the sample of mothers of children with sensory and physical impairments was relatively small. Therefore caution must be taken when interpreting these results.

In terms of clinical implications, therefore, clinicians need to be aware of issues not necessarily associated with specific problems presented within their clinic. Especially in relation to the presence of challenging behaviours, the number of challenging behaviours displayed and the availability of the mother's personal and socio-ecological resources to help her manage these difficulties. If challenging behaviour develops as a result of an insecure attachment between the mother and her child (Janssen et al, 2002), and if challenging behaviour has such an impact upon parenting behaviour (Hastings, 2002), it is essential that the presence of challenging behaviour is assessed and an appropriate intervention developed in an attempt to directly influence the mother's experience of stress and thereby indirectly influence her parenting behaviour and improve the bond between her and her child. In addition, in accordance with recommendations made by "The Same As You" individuals with a learning disability should have access to services that meet every day needs and additional complex needs. This suggests that, as well as providing generic services for children with learning disabilities, services should be developed that focus specifically on complex needs, such as, the management of challenging behaviour and the impact this has upon the wider family.

Hypothesis three suggested that mothers of children with learning disabilities were more likely to score higher on the BDI, than mothers of children without learning disabilities and that this increased vulnerability to depression would be associated with increased levels of stress. This study found that mothers of children with learning disabilities were significantly more likely to obtain scores on the BDI within the mild, moderate and severe risk categories than mothers of children without learning disabilities. In addition, when comparing total BDI scores, mothers of children with learning disabilities scored significantly higher on the BDI than mothers of children without learning disabilities. This supports that found by Hoare et al, (1998), & Veisson, (1999).

It is important therefore, that clinicians address issues beyond those specifically associated with the child. The dynamic and reciprocal nature of the relationship between the mother and her child suggests that both characteristics of the child and their mother may be serving to maintain their difficulties and are likely to have an impact upon the outcome of any intervention.

Stressful events and the way in which they are interpreted play an important role in the onset and course of depression (Beck, 1987). This would suggest that depression and stress would be positively correlated. In this study BDI scores and QRS-F scores were positively correlated, suggesting that as mothers of children with learning disabilities' experience of stress increases, so too does their risk of developing depression. However, this correlation was not found to be significant. Clinically, therefore, this implies that it cannot be assumed that someone who reports a significant degree of stress is depressed or vice versa. The experience of depression may create a sense of detachment from the environment, in which case, stress may be perceived differently from someone who is not depressed. On the other hand, the experience of stress may result in the individual seeking out more services or supports to enable them to cope more

effectively with the stress they experience, in which case, they may subconsciously utilise protective strategies, and, as a result, avoid developing depression.

Hypothesis four was concerned with environmental factors influencing the mother's experience of stress. Philip and Duckworth (1982) found that mothers of children with learning disabilities were more likely to feel socially isolated than mothers of children without learning disabilities. Therefore, it was hypothesised that mothers of children with learning disabilities would have less social supports than mothers of children without learning disabilities. However, in this study there were no significant differences between the groups in terms of the total number of supports they had. In addition, it was hypothesised that mothers of children with learning disabilities would use more professional supports than mothers of children without learning disabilities. This was indeed found to be the case.

In addition, it was hypothesised that there would be no difference in terms of the perceived helpfulness of supports received by both groups. This was found to be the case. However, mothers of children with learning disabilities were more likely to find services provided by professionals helpful, than mothers of children without learning disabilities.

Florian & Krulik (1991), suggest it is the perceived helpfulness of the supports received rather than the number of supports available that is of most importance in the alleviation of stress. Therefore it cannot be assumed that the number of services received and the perceived helpfulness of those services will be positively correlated. In this study, however, a significant positive correlation *was* found between the total number of supports indicated by both groups and the perceived helpfulness of those supports received.

However, looking at responses made by mothers of children with learning disabilities in terms of each group of supports measured by the FSS (formal kin, informal kin, partner related support, social organisations and professional services), a significant positive correlation was only found between the number of formal kin supports and their helpfulness. This suggests that, as the number of supports from formal kin, such as the mother's parents and the mother's relatives, increase, so too does her perception of their helpfulness. It is important to note that there were no further significant results between the number of supports available within each group of supports measured by the FSS and their perceived helpfulness. As a result of this, therefore, it is important that clinicians identify how many supports are available to mothers of children with learning disabilities and how helpful they perceive these supports as it appears that these two factors are not necessarily positively correlated.

Before discussing the impact the availability and satisfaction with social support has upon the experience of stress for mothers of children with learning disabilities, additional environmental factors will be discussed to identify their influence. Firstly, it has been found that single parenthood can have a negative impact upon the stress experienced by a mother of a child with learning disabilities (Beckman, 1984). This study found however, that there were no significant differences in QRS-F scores reported by married mothers and single mothers of children with learning disabilities, thus supporting the notion that there is no relationship between marital status and maternal stress in families of children with learning disabilities (McCubbin & Hwang, 1989). However this may be a result of the fact that mothers were asked whether they were married or single only and there was no opportunity to indicate that they were living with a partner or received additional help and support from a boyfriend. This is consistent with the findings of Fagan & Schor (1993), who identified that marital status did not predict maternal satisfaction and adjustment, but the presence of adult companionship did. Alternatively, in this



sample, single mothers may have received additional formal kin supports to compensate for a lack of partner related supports.

It has also been found that parents with higher levels of education and income coped more effectively with their child with learning disabilities (Barber et al, 1989 & Quine & Pahl, 1985). In this study, however, there was no significant difference in QRS-F scores in terms of the occupation of the main earner for mothers of children with learning disabilities. Again this may have occurred as a result of the way in which socio-economic status was measured in this study. The occupation of the main earner was obtained and categorised in terms of unemployed, manual worker and professional. This takes no account of additional income, such as inheritance, and expendable income can only be discussed in terms of outgoings, and this may differ substantially in terms of the level of their child's ability.

Mothers of children with learning disabilities report higher levels of burden than mothers of children without learning disabilities (Bailey et al, 1991), and it is argued that this sense of burden will increase as the number of dependant children living at home increases. This study found a positive correlation between the number of children living at home and scores on the QRS-F, however this result was not significant. It cannot be assumed therefore that more children living at home increases the experience of stress for the mother, indeed siblings may provide invaluable additional support to their mother in terms of looking after their sibling with learning disabilities. (Kaminsky & Dewey, 2002)

Finally, Frey et al (1989) suggested that the availability of social support and satisfaction with that support predicted adjustment for mothers to children with developmental delay. However, it has already been discussed that the number of supports a mother receives in relation to bringing



up her child with learning disabilities may not be the most important factor in terms of reducing her stress, but the perceived helpfulness of those supports may be of much greater importance. There was a negative correlation between the number of supports mothers of children with learning disabilities indicated and QRS-F scores, suggesting that as the number of supports increase the level of reported stress decreases. However, these results were not significant.

A significant negative correlation, however, was found between the perceived helpfulness of supports received by mothers of children with learning disabilities and QRS-F scores. This is consistent with Florian & Krulik's, (1991) findings that it is the perceived helpfulness of supports that has an impact upon levels of reported stress and not necessarily the number of supports one receives.

## 5.2 Summary of Results

The results found in this study are consistent with those found by Weiss, (2002), Baxter et al, (2000), Dyson, (1997), and Quine and Pahl, (1985), that mothers of children with learning disabilities experience more stress than mothers of children without learning disabilities. In addition, mothers of children with learning disabilities, in this sample, reported that their child displayed more challenging behaviours than mothers of children without learning disabilities. Although there was no significant association between the presence of sensory and physical impairments and reported levels of stress, and the presence of challenging behaviour and reported levels of stress experienced by the child's mother, the *number* of challenging behaviours displayed *was* significantly positively correlated with increased levels of stress. In terms of characteristics of the mother, mothers of children with learning disabilities reported higher levels of depression, as measured by the BDI than mothers of children without learning disabilities, and, although not significant, a positive correlation was found between levels of stress and depression. Finally, mothers of children with learning disabilities did not differ from mothers of children without learning disabilities in terms of the number of supports they had, or the perceived helpfulness of these supports. Although, when looking at forms of support, mothers of children with learning disabilities used more professional services than mothers of children without learning disabilities and they found these services more helpful than mothers of children without learning disabilities.

Florian & Krulik (1991) suggested that the perceived helpfulness of supports was more important in reducing stress than the number of supports. This raised the issue that the number of supports may not be associated with their perceived helpfulness. In terms of the total sample,

this was not the case, and there was a significant positive correlation between the total number of supports and their perceived helpfulness. However, when looking more closely at the five areas of support measured by the FSS in the research group, there appeared to be some negative correlations between the number of supports received and their perceived helpfulness, suggesting that one cannot assume that as long as someone is receiving plenty of supports, they necessarily find these supports helpful. In this study marital status, socio-economic status (as measured by the occupation of the main earner), the number of children living at home and the number of supports available, did not have a significant impact upon levels of stress. However, the perceived helpfulness of the supports received was significantly negatively correlated with levels of stress.

Although these appear interesting results, in terms of identifying those factors that may have an impact upon the mother's experience of stress, there are several factors that have not been examined due to the time limit imposed upon this study. These factors include, the child's age, level of ability and diagnosis; the mother's personal coping resources, such as, her own physical health, her beliefs and ideologies about her child and her parenting skills; and environmental characteristics, such as, family functioning. In addition, it is difficult to discuss the factors examined in this study in isolation, due to the inter-related nature of their influence.

The environment exerts a significant influence upon the child and the child in turn exerts a significant influence upon its environment. The child's mother represents a significant figure within the child's environment, in terms of her role as a figure of attachment and her capacity to provide a safe environment in which the child develops. The mother of a child with learning disabilities faces a variety of challenges in terms of bringing up her child and these challenges relate to characteristics of the child, their mother and the environment. In terms of bonding, the

degree of responsiveness, affection and emotional closeness displayed by the child influences the nature of the relationship between the mother and her child (Hoppes & Harris 1990). Significant challenges are apparent for mothers of children with autism, who display limited activity, crying, lack of responsiveness and passivity (Minnes, 1998). A child with learning disabilities is more likely to display challenging behaviour than a child without learning disabilities (Rutter, et al, 1970 & Dykens, 2000 ) and the mother of a child with learning disabilities is more likely to experience depression than a mother of a child without learning disabilities (Hoare et al, 1998, & Veisson, 1999). In addition, factors of socio-economic status and marital status can have an impact upon a mother's ability to cope successfully with her child.

The nature of the dynamic, reciprocal relationship (Lewis & Rosenblum, 1974) between the mother and her child, means that it is difficult to establish causality in terms of the impact of factors and as such, one can only be aware of the presence of these factors in each mother / child relationship and attempt to work with the needs of each family.

These challenges can have a negative impact upon the relationship between the mother and her child, however, factors such as social support has been found to have a buffering effect upon the difficulties experienced by the mother of a child with learning disabilities (Sloper & Knussen, 1991 & Beresford & Lawton, 1993). The availability of social support and the satisfaction with the support received can lead to positive adjustment (Frey et al, 1989) and family integrity and lowered maternal stress (Dyson and Fewell, 1986) for mothers of children with learning disabilities. This study has attempted to look at some of these factors. However there are a number of limitations that should be considered when interpreting the results of this study.

### 5.3 **Methodological Issues**

#### 5.3.1 *Methodological Issues with Design of Study*

This study was based upon a questionnaire design, presented as a semi-structured interview, where mothers of children with and without learning disabilities were asked to respond to each section of the questionnaire in the presence of the researcher. This style of design and presentation presents a number of methodological issues.

In terms of using a series of self-report measures, Oppenheim (1992) raises the issue of participants responding in a socially desirable manner. In this study, this may have been a particularly pertinent issue as the researcher presented many of the questionnaires verbally to participants, thus requiring the participants to respond in a similar manner. This may have resulted in socially desirable responses. It is argued, however, that research subjects appeared motivated to respond honestly in an attempt to highlight their own personal needs. This has been highlighted in the results, which have clearly identified that mothers of children with learning disabilities are significantly more likely to experience stress and depression than mothers of children without learning disabilities. However, the same cannot be said for the control group, who may have answered in a socially desirable fashion to save face in front of the researcher.

Several design effects have been highlighted by Powell (1996), and those relevant to this study will be discussed. The experimenter effect refers to the participant trying to please the researcher and this has already been discussed. The leniency error refers to individuals resisting the assignment of negative qualities to themselves or others. This is closely linked to the

experimenter effect and may be associated with the need to provide socially desirable responses. In terms of both groups, therefore, it may have proved difficult to acknowledge their experience of stress or indeed to acknowledge that they may be at high risk of depression. In addition, they may have found it difficult to assign negative statements to their child, when answering the challenging behaviour questionnaire and the QRS-F. From the results obtained, there may have been a bias towards socially acceptable responses from the control group, but a bias in the opposite direction for mothers of children with learning disabilities, who appeared keen to highlight the extent of their difficulties. Powell (1996) refers to this phenomenon as “extreme responding,” where participants tend to respond at extreme ends of the scale. From the data, however, this did not appear to be the case, with the direction of responses being variable.

The questionnaires were presented in a semi-structured interview in order to overcome any literacy difficulties. However, to counter some of the potential biases discussed above, if participants were literate, they were given the QRS-F and the BDI to complete independently. The researcher, however, remained present and it is therefore debateable if these biases were overcome. In an attempt to reduce a socially acceptable response bias, it must be acknowledged that an additional bias between literate and illiterate participants was introduced, in terms of the mode of questionnaire administration. Regardless of the administration of the questionnaires, the same methodological issues associated with the use of questionnaires still exist and as Powell (1996) suggests, “no test is ideal and the problems posed by this error component have to be squarely faced”

### 5.3.2 *Methodological Issues with the Sample*

In terms of having obtained a representative sample of mothers of children with learning disabilities, several factors must be discussed. Research subjects were obtained through the local paediatric special needs clinic, as it was felt that this environment would provide the researcher with a cross-sectional sample of the population of mothers of children with learning disabilities living in the local area. All mothers of children with learning disabilities passing through the special needs clinic over a five month period were asked if they would like to take part in the project. It is suggested that, in terms of a sampling bias, those individuals either most in need of help and support, and those who felt strongly about the lack of services available to them are likely to have made up the majority of the sample obtained. This may explain the significant figures obtained in terms of the stress, depression and high degree of challenging behaviour reported by this group. In addition, a third of mothers in the research group were unemployed, in comparison to 10% of the control group and mothers of children with learning disabilities had larger families than mothers of children without learning disabilities. Although these factors were found not to have a significant impact upon QRS-F scores and BDI scores, it is important to note that those individuals who came forward were from backgrounds where additional stressors were likely to exist.

In addition, within the research group, mothers were not asked their age. However, studies have found that maternal age does not reliably predict stress or maternal mental ill-health in mothers of children with learning disabilities (Beckman, 1984, & Ryde-Brandt, 1990). Due to time limitations imposed upon this study, the degree of the child's learning disability could not be determined. There has been limited research looking at stress associated with the degree of the child's learning disability, although it is argued that the more severe the learning disability, the

more likely the child will present with additional problems such as epilepsy, challenging behaviour, sensory and physical impairments. From the literature, it is the presence of these additional factors that appears to have an impact upon the stress experienced by the mother of a child with learning disabilities (Quine & Pahl, 1985), and as such it was felt that the level of ability per se did not have to feature as a variable in this study.

Mothers were asked to indicate if their child had received a diagnosis, and if so, they were asked to highlight this. However, sufficient numbers were not obtained to conduct meaningful analysis on how the nature of the child's diagnosis affected the stress experienced by their mother. Returning to a previous argument, those studies that have highlighted an increase in stress associated with a child's diagnosis, appear to highlight the role of challenging behaviour as a contributory factor to this increase in stress (Hodapp et al 1997, & Dumas 1991), and therefore these additional factors may be more important in terms of the likelihood of the mother experiencing stress, than the diagnosis itself.

This study focused exclusively upon mothers of children within the school-age range. This was also a fault of Dyson, (1993 & 1997). This sampling bias, therefore, resulted in mothers of pre-school-age children being excluded from this study. Due to the limited time imposed upon this research, further analysis, in terms of the impact age had upon the experience of stress for the child's mother, was not conducted upon this factor.

In terms of selection of the control group, there was a significant lack of response from the letters sent out to mothers randomly selected from a local GP practice database. This may have been due to a number of factors including the fact they were only contacted by post and not followed up by a phone call, or indeed that the information sent to them was unclear in some



way (Appendix 2). As a result of this, and due to the time limitations imposed upon the researcher, local health care professionals and their friends were asked to become involved. This is likely to have influenced the fact that a matched sample was not obtained. In the control group, over 60% indicated that the occupation of the main earner was professional, compared to 40% of the total research group. In addition, by asking local health care professionals to become involved, this is likely to have increased the risk of a potential halo effect. This population are likely to have felt under pressure to answer in a socially desirable fashion due to their involvement with children within the NHS.

In summary, every attempt was made to obtain a representative sample of mothers of children with learning disabilities, and yet, it is likely the sample was made up largely of those who were in the most need of help or a few who were vocal enough to express a need for more services for themselves and their child. As a result of this, and due to the measures that had to be taken to ensure a control group was obtained in time, the two groups were not matched in terms of the occupation of the main earner or indeed the number of children living at home. It was felt that these factors may have had an adverse effect upon QRS-F scores and BDI scores, although, further analysis found that neither of these factors had a significant impact upon QRS-F and BDI scores.

### *5.3.3 Methodological Issues with the Measures Used*

The first questionnaire provided the researcher with demographic information relating to the mother's current family situation. In addition, mothers of children with learning disabilities were asked about their child with disabilities, whether they felt they received enough support

and if not, what additional supports did they require. This measure was based on factual information and it is therefore assumed that answers were reliable and valid.

The second questionnaire asked participants whether their child displayed any challenging behaviour and asked them to indicate, from a list of options, what form of challenging behaviour their child displayed. Emerson (1998) argues that challenging behaviour is a social construction and is defined by its impact. Therefore, the definition of challenging behaviour will vary depending upon who finds the behaviour challenging and where, when and why the behaviours are being displayed. Thus suggesting that defining what is challenging is largely subjective. This was acknowledged and options were given to participants to rule out any uncertainty they may have had with regard to defining different forms of challenging behaviour. This removed the subjectivity of participant's responses and created consistency within responses. However, it can be argued that the nature of this forced-choice limited participant's responses and may have failed to identify individual perceptions of behaviours they found challenging. In this study, mothers were not given the opportunity to indicate the intensity of challenging behaviour displayed. It could be argued that the intensity of behaviour displayed may have a stronger influence upon levels of self-reported stress, than the presence of challenging behaviour alone.

The Beck Depression Inventory (Beck et al, 1996) was used, not as a diagnostic measure, but to identify the degree of risk of depression apparent in mothers of children with learning disabilities. This measure was inconsistently administered. In some cases, where the mother displayed literacy problems, the researcher read out each of the questions and options to the participant. Where there were no literacy problems, mothers were asked to complete the BDI themselves as it was felt that participants would answer more honestly if completing the BDI independently.

The Friedrich Short-Form of the Questionnaire on Resources and Stress was used to measure the levels of stress in mothers of children with learning disabilities and mothers of children without learning disabilities. Holroyd et al, (1975) demonstrated the ability of the QRS to discriminate among parents of children with learning disabilities and parents of children without learning disabilities. However, a differential response was observed in mother's responses on the QRS-F. The QRS-F was originally designed for families of children with learning disabilities and therefore may "predispose the emergence of group differences" (Stoneman, 1989). This may have accounted for the large differences between responses made by mothers of children with learning disabilities and those responses made by mothers of children without learning disabilities. However, "the differential responses may also indicate that the effect of a child's disability on parents is specific to only certain areas of the child's disability such as those measured by the QRS-F."(Dyson, 1993). It is argued, however, that the physical incapacity factor on the QRS-F was biased towards positive responses by mothers of children with learning disabilities. However, the other three factors including the family problems factor, the pessimism factor and the child characteristics factor incorporated elements associated with both children with and without learning disabilities. Friedrich et al (1983) suggest that further research should focus on analysing the ability of the QRS-F to discriminate between families of children with learning disabilities and families of those for whom there is no concern about their development.

The Family Support Scale (Dunst et al, 1984) provides examples of 18 sources of support and asks participants to indicate on a six point likert scale how helpful they find each source of support. Although an indication of few supports with low helpfulness ratings is thought to indicate an unsupported individual, the FSS gives no opportunity for respondents to indicate whether they feel they receive adequate supports and, if not, what supports do they feel they are

lacking. The researcher incorporated these questions, therefore, into the demographic questionnaire.

## 5.4 Conclusions

In conclusion, this study has aimed to identify whether mothers of children with learning disabilities experience more stress than mothers of children without learning disabilities and has attempted to identify the impact of factors relating to the child, their mother and the environment, upon the mother's experience of stress. The results highlight the importance of looking beyond the needs of the individual child, towards the needs of the mother and indeed the family as a whole. This study has addressed the needs of the mother specifically, due to the unique reciprocal relationship between the mother and her child. However, the child's environment is not exclusively made up of the child and their mother and as such one cannot disregard the relationship between the child and their father, their siblings, their extended family and the world beyond.

Although the results indicate that mothers of children with learning disabilities report higher levels of stress, as measured by the QRS-F, than mothers of children without learning disabilities, it cannot be assumed that mothers of children with learning disabilities are a homogenous group of individuals. In several cases, mothers of children with learning disabilities have been found to cope successfully and keep stress levels under manageable control (Gallagher, 1981). Winzer, (1990) also found that the "presence of a family member with a disability may contribute to the strengthening of the entire family." Although it has been highlighted that several factors can increase a mother's experience of stress, Yau & Li-Tsang (1999) emphasise that; "..... it is important that professionals view every parent, child and family as unique, with their own set of needs and concerns within their own living context."

They continue by illustrating the importance of tailoring interventions specifically to meet the needs of each family. Warfield et al (1999) acknowledged that families experience a range of stressors that are not related to their child with learning disabilities. He suggested that there is significant variability in relation to child-related stress experienced by families, and environmental characteristics, such as cohesion, income and support were the greatest predictors of stress. Therefore, clinicians must be aware that mothers of children with learning disabilities, like mothers of children without learning disabilities, may experience stress as a result of factors unrelated to their child.

To conclude, therefore, although this study has found that mothers of children with learning disabilities are more likely to experience stress, it is important for clinicians to view each child within the context of their family and to acknowledge that stress experienced by the mother may be associated with stressors unrelated to their child. However, clinicians should be aware that the mother's experience of stress can have a significant impact upon the environment in which the child with learning disabilities lives and indeed upon the child themselves. In addition, clinicians should be aware that, the issues that appear to have an impact upon the experience of stress in mothers of children with learning disabilities, include, the presence of challenging behaviour in their child, maternal depression and, not only the presence, but the perceived helpfulness of supports available to them. This should inform the development of services for children with learning disabilities, especially in Scotland, where services are limited. In light of the inter relationship between a child with learning disabilities and its environment, services should be developed to address issues such as challenging behaviour, adaptive family functioning, maternal depression; and should encourage the development of social support networks for mothers of children with learning disabilities by facilitating parental support groups.

## 5.5 Suggestions for Future Research

Due to time limitations, this study selected a limited number of factors relating to the child, their mother and the environment, in an attempt to identify the impact of these factors upon stress experienced by the mother of a child with learning disabilities. Future research, should attempt to study additional factors that have not been analysed in the present research. These include; child characteristics such as, the child's age, level of ability and diagnosis; maternal characteristics, such as, the mother's physical health, her beliefs and ideologies about her child and the future and her parenting skills; and finally, environmental characteristics, such as, family functioning. It is argued that further analysis of these factors would facilitate our understanding of the factors that may contribute to the mother of a child with learning disabilities' experience of stress and may improve our understanding of the inter-relationship between these factors.

In addition, returning to our preliminary discussions about the relationship between a child with learning disabilities and their mother, further research should attempt to identify the impact of stress and depression upon the attachment between the child and their mother. It is argued that further analysis of attachment may be fundamental in developing our understanding of the relationship between the child with learning disabilities and its mother, the difficulties they face, and in advancing our knowledge about the causal nature of these difficulties. Further analysis of the experience of stress *within* a group of mothers of children with learning disabilities would improve our understanding of the range of reactions and experiences faced by these mothers and would reduce the likelihood of clinicians assuming that mothers of a child with learning disabilities are part of a homogenous group.

A child with learning disabilities lives within a dynamic environment that rarely consists solely of the child and their mother. As such, further research should attempt to analyse the inter-relationship between a child with learning disabilities and other members of their family, including the relationship between the child and their father, or, indeed, their siblings.

The relationship between a child with learning disabilities and their environment is a constantly evolving process. Therefore, adopting a longitudinal design in an attempt to understand the nature of this relationship would help determine each family members experience across the life span.

In terms of design and sampling issues, a measure of stress should be identified that reliably and validly measures differences between family members of those with a child with learning disabilities and those without. In addition, when comparing family members of children with a learning disability with a control group, every attempt should be made to obtain a matched sample, in order that reliable conclusions can be drawn about the differences between these two groups. Larger numbers of participants increase the statistical power of a test and reduce the risk of mistakenly rejecting the null hypothesis. Therefore, further research should attempt to recruit a larger sample of participants to improve the representation of the population as a whole.







## **References**

- Aitken, R.C.B (1969). A growing edge of measurement of feelings. *Proceedings of the Royal Society of Medicine*, **62**, pp. 989-996.
- Alexander, D., & Klein, D. (2000). Bad news is bad news: Lets not make it worse, *Trauma*, **2** (1), pp. 11-18.
- Anderson, C.A., & Hammen, C.L. (1993). Psychosocial outcomes of unipolar, bipolar, medically ill, and normal women: A longitudinal study. *Journal of Consulting and Clinical Psychology*, **61**, pp. 448-454.
- Ayer, S. (1984). Community Care: failure of professionals to meet family needs. *Child: Care, Health and Development*, **10**, pp. 127-140.
- Bailey, D.B., Blasco, P.M., Simeonsson, R.J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation*, **97**, pp. 1-10.
- Bailey, N.M. & Cooper, S.A. (1997). The current provision of specialist health services to people with learning disabilities in England and Wales. *Journal of Intellectual Disability Research*, **41**, 52-9.
- Barber, P.A., Turnbull, A.P., Behr, S.K. and Kerns, G.M. (1988). A family systems perspective on early children special education. In S.L. Odom & M.B. Karnes (Eds.), *Early Intervention for Infants and Children with Handicaps*, (pp. 179-198). Baltimore: P.H. Brookes Publishing Co.
- Barrera, M. & Ainlay, S.L. (1983). The structure of social support – a conceptual and empirical analysis. *Journal of Community Psychology*, **11**, pp. 133-143.
- Baxter, C., Cummins, R.A., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual & Developmental Disability*, **25**(2), pp 105-118.
- Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). *Cognitive Therapy of Depression*. New York: Guildford press.
- Beck, A.T. (1987). Cognitive models of depression. *Journal of Cognitive Psychotherapy: An International Quarterly*, **1**, pp. 5-37.
- Beck, A.T., Steer, R.A., & Brown, G.K. (1996). *Manual for the Beck Depression Inventory*. San Antonio, TX: The Psychological Corporation.
- Beckman, P. (1983). Influence of selected child characteristics on stress in families of handicapped infants. *American Journal of Mental Deficiency*, **88**, pp. 150-156.
- Beckman, P.J. (1984). Perceptions of young children with handicaps: a comparison of mothers and program staff. *Mental Retardation*, **22**, pp. 176-181.

Beckman P.J. (1991). Comparison of Mother's and fathers perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95 (5), pp. 585-595.

Bell, R.Q. (1968). A reinterpretation of effects of studies of socialisation. *Psychological Review*, 75, 81-95.

Belsky, J., & Nezworski, T. (1988). *Clinical Implications of Attachment*. Hillsdale, NJ: Lawrence Erlbaum.

Beresford, B.A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35 (1), pp171-209.

Beresford, B.A., & Lawton, D. (1993). Coping with the care of a severely disabled child: Final report to the Joseph Rowntree Foundation. JRF 1078, Social Policy Research Unit, University of York.

Blacher, J., Nihira, K., & Meyers, C.E. (1987). Characteristics of home environment of families with mentally retarded children: Comparison across levels of retardation. *American Journal of Mental Deficiency*, 91, pp. 313-320.

Blacher, J., & Lopez, S. (1997). Contributions to depression in Latina mothers with and without children with retardation: implications for care giving. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 46, pp. 325-334.

Blacher, J., Shapiro, J., Lopez, S., Diaz, L., & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation: a neglected concern. *American Journal on Mental Retardation*, 101, pp. 483-496.

Blair, M.E., Pullan, C.R., Rands, C.E. & Crown, N. (2000). Community Paediatricians move on – an analysis of changing work patterns. *Public Health*, 114, 61-64.

Bowlby, J. (1958). The nature of the child's tie to its mother. *International Journal of Psychoanalysis*, 39, 350-373.

Bregman, J.D. (1991). Current developments in the understanding of mental retardation. Part II: psychopathology. *Journal of the American Academy of Child and Adolescent Psychiatry*, 30, pp. 861-872.

Breslau, N., Staruch, K.S., & Mortimer, E.A. (1982). Psychological distress in mothers of disabled children. *American Journal of Diseases of Children*, 136, pp. 682-686.

Bristol, M.M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G.B. Mesibov (Eds.), *The Effects of Autism on the Family* (pp. 289-310), New York: Plenum.

Bristol, M.M., & Schopler, E. (1984). A development perspective on stress and coping in families of autistic children. In J. Blacher (Ed.), *Severely Handicapped Children and their Families*, (pp. 91-141). New York: Academic Press.

British Paediatric Association (1994). Services for children and adolescents with learning disability (Mental Handicap). Report of a BPA working party. London: BPA.

- Brofenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge, MA: Harvard University Press.
- Brown, G.W., & Harris, T.O. (1978). Social origins of depression: A study of psychiatric disorder in women. Tavistock Publications, London.
- Bruce, E.J., Schultz, C.L., & Smyrnois, K.X. (1996). A longitudinal study of the grief of mothers and fathers of children with intellectual disability. *British Journal of Medical Psychology*, **69**, 33-45
- Bruce, E.J., Schultz, C.L., Smyrnios, K.X., & Schultz, N.C. (1994). Grieving related to development: A preliminary comparison of three age cohorts of parents of children with intellectual disability. *British Journal of Medical Psychology*, **67**, 37-52)
- Byrne, E.A., & Cunningham, C.C. (1985). The effects of mentally retarded children on their families: A conceptual framework. *Child Psychology and Psychiatry*, **26**, pp. 847-864.
- Byrne, E.A., Cunningham, C.C., & Sloper, P. (1988). Families and their children with Down's syndrome: one feature in common. London: Routledge.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, **112** (1), pp. 155-159
- Coyne, J.C., & Smith, D.A.F. (1991). Couples coping with a myocardial infarction: a contextual perspective on wives' distress. *Journal of Personality and Social Psychology*, **61**, pp 404-412.
- Crnic, K. (1990). Families of children with Down's syndrome: Ecological contexts and characteristics. In D. Cicchetti & M. Beeghly (Eds.), *Children with Down's syndrome: A Developmental Perspective* (pp. 399-423). New York: Cambridge University Press.
- Cummings, S., Bayley, H., & Rie, H. (1966). Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. *American Journal of Orthopsychiatry*, **36**, 595-608.
- Darling, N., & Steinberg, L. (1993). Parenting styles as context: An integrative model. *Psychological Bulletin*, **113**, 487-496.
- Deaton, A.V. (1985). Adaptive non-compliance in paediatric asthma – the parent as expert. *Journal of Paediatric Psychology*, **10**, pp. 1-14.
- Deb, S. and Prasad, K.B. (1994). Prevalence of autistic disorder among children with a learning disability. *British Journal of Psychiatry*, **165**, 395-9.
- Department of Health. The Children's 1989 Guidance and recommendations Volume 6. Children with Disabilities. London: HMSO, 1992.
- Dohrenwend, B.S., & Dohrenwend, B.P. (1974). Stressful life events: Their Nature and Effects. Wiley, New York, NY.
- Donovan, A. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation*, **92**, 502-509.

- Downey, G., & Coyne, J.C. (1990). Children of depressed parents: An integrative review. *Psychological Bulletin*, **108**, pp. 50-76.
- Dumas J.E., Wolf L. C., Fisman S.N., Culligan A. (1991). Parenting stress, child behaviour problems, and dysphoria in parents of children with autism, Down's syndrome, behaviour disorders, and normal development. *Exceptionality*, **2**, pp97-110.
- Dunst, C.J., Jenkins, V., & Trivette, C.M. (1984). The Family Support Scale: Reliability and validity. *Journal of Individual, Family and Community Wellness*, **1**, pp. 45-52.
- Dunst, C.J., & Trivette, C.M. (1990). Assessment of social support in early intervention programs. In S.J. Meisels, & J.P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention* (pp. 326-349), New York: Cambridge University press.
- Dykens, E.M. (2000). Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry*, **41**, pp. 407-417.
- Dyregrov, A., & Matthiesen, S.B. (1987). Similarities and differences in mothers' and fathers' grief following the death of an infant. *Scandinavian Journal of Psychology*, **28**, pp. 1-15.
- Dyson, L., Edgar, E., & Crnic, K. (1989). Psychological predictors of adjustment by siblings of developmentally disabled children. *American Journal on Mental Retardation*, **94**, pp. 278-283.
- Dyson L.L. (1993). Response to the presence of a child with disabilities: parental stress and family functioning over time. *American Journal on Mental Retardation*. **98** (2), pp207-218.
- Dyson, L.L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal on Mental Retardation*, **102**, 267-279.
- Dyson, L., & Fewell, R.R. (1986). Stress and adaptation in parents of young handicapped and non-handicapped children: A comparative study. *Journal of Division for Early Childhood*, **10**, pp. 25-35.
- Emerson, E. (1998). Working with people with challenging behaviour. In E. Emerson, C. Hatton, J. Bromley, & A. Caine (Eds.), *Clinical Psychology and People with Learning Disabilities*. John Wiley & Sons.
- Erickson, M., & Upshur, C.C. (1989). Care taking burdens and social support: Comparison of mothers of infants with and without disabilities. *American Journal on Mental Retardation*, **94**, pp. 250-258.
- Fagan, J., & Schor, D. (1993). Mothers of children with spina bifida: Factors related to maternal psychological functioning. *American Journal of Orthopsychiatry*, **63**, pp. 146-152.
- Farber, B. (1959). The effects of a severely retarded child on family integration. *Monographs of the society for research in child development*, **24** (2).
- Farber, B. (1960). Family organisation and crisis: Maintenance of integration families with a severely mentally retarded child. *Monographs of the Society for Research in Child Development*, **25** (1).

- Fernald, C.D. (1995). When in London....Differences in disability language preferences among English speaking countries. *Mental Retardation*, **33**, 99-103.
- Festinger, L. (1957). *A Theory of Cognitive Dissonance*. Evanston, III: Row, Peterson.
- Fewell, R. (1986). A handicapped child in the family. In R. Gewell & P. Vadasy (Eds.), *Families of Handicapped Children* (pp. 3-34). Austin, TX: Pro-Ed.
- Florian, V., & Krulik, T. (1991). Loneliness and social support. *Social Science and Medicine*, **32**, pp. 1292-1296.
- Flynt S.W. & Wood T.A. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation*, **94** (3), pp278-283.
- Fortier, L.M., & Wanlass, R.L. (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations*, **33**, 13-24.
- Frey, K.S., Fewell, R.R., & Vadasy, P.F. (1989). Parental adjustment and changes in child outcome among families of young handicapped children. *Topics in Early Childhood Special Education*, **8**, pp. 38-57.
- Friedrich, W.N. (1979). Predictors of coping behaviour of mothers of handicapped children. *Journal of Consulting and Clinical Psychology*, **47**, pp. 1140-1141.
- Friedrich, W.N., Greenberg, M.T., & Crnic, K. (1983). A short form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency*, **88** (1), pp. 41-48.
- Friedrich W.N., Wiltturner L.T., & Cohen D.S. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency*, **90** (2), pp. 130-139
- Gallagher, J.J., Cross, A., & Scharfman, W. (1981). Parental adaptation to a young handicapped child: The father's role. *Journal of the Division for Early Childhood*, **3**, pp. 3-14.
- Gangadharan, S. Bretherton, K. and Johnson, B. (2001). Pattern of referrals to a child learning disability service. *The British Journal of Developmental Disabilities*, **47**, Part 2, No. 93, 99-104.
- Gough, D., Li, L., & Wroblewska, A. (1993). Services for children with a motor impairment and their families in Scotland. University of Glasgow: Public health Research Unit.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, **42** (1), pp 58-71.
- Harris, V.S., & McHale, S.M. (1989). Family life problems, daily care taking activities, and the psychological well being of mothers of mentally retarded children. *American Journal on Mental Retardation*, **94**, pp. 231-239.
- Hastings R.P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability*, **27** (3), pp. 149-160.

- Hastings R.P. & Remington, B. (1994). Staff behaviour and its implications for people with learning disabilities and challenging behaviour. *British Journal of Clinical Psychology*, **33**, p423-438.
- Hill, R (1958). Generic features of families under stress. *Social Casework*, **49**, 139-150.
- Hoare P., Harris M., Jackson P. & Kerley S. (1998). A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research*, **42** (3), pp 218-227.
- Hodapp, R.M, Dykens, E.M., & Masino, L.L. (1997). Families of children with Prader-Willi Syndrome: Stress-support and relations to child characteristics. *Journal of Autism and Developmental Disorders*, **27** (1), pp. 11-24.
- Holroyd, J. (1974). The questionnaire on resources and stress: An instrument to measure family responses to a handicapped family member. *Journal of Community Psychology*, **2**, pp. 92-94.
- Hoppes, K., & Harris, S.L. (1990). Perceptions of child attachment and maternal gratification in mothers of children with autism and Down's syndrome. *Journal of Clinical Child Psychology*, **19**, 365-370.
- Horowitz, F.D. (1987). Exploring developmental theories: Toward a structural / behavioural model of development. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Howell, D.C. (1997). *Statistical Methods for Psychology*, Wadsworth Publishing Company, Thomson Publishing Inc.
- James, A. (2001). *Hearing the Worst*, The Guardian Society, 25<sup>th</sup> April: 5.
- Janssen C.G.C., Schuengel C., Stolk J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: a stress- attachment model. *Journal of Intellectual Disability Research*, **46** (6), pp. 445-453.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, **43** (2), pp. 225-232.
- Kazak, A.E., & Wilcox, B. (1984). The structure and functioning of social support networks in families with handicapped children. *American Journal of Community Psychology*, **12**, 645-661.
- Kennedy, J.F., (1970). Maternal reactions to the birth of a defective baby. *Social Casework*, **51**, pp. 410-417.
- Krauss, M.W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation*, **97** (4), pp. 393-404.
- Kurstjens, S., & Wolke, D. (2001). Effects of maternal depression on cognitive development of children over the first 7 years of life. *Journal of Child Psychology and Psychiatry*, **42** (5), pp. 623-636.



- Lazarus, R.S., & Folkman, S. (1984). Coping and adaptation. In W.D. Gentry (ed.), *Handbook of Behavioural Medicine*. New York: The Guildford Press.
- Lazarus, R.S., & Folkman, S. (1984a). *Stress, Appraisal and Coping*. New York: Springer.
- Lee, G. (1979). Effects of social networks on the family. In W.R. Burr, R. Hill, R.I. Nye, & I.L. Reiss. *Contemporary Theories about the Family: research-based theories*. Volume 1. New York: Free Press.
- Lewis, M., & Rosenblum, L.A. (1974). *The Effect of the Infant on its Caregiver*. New York: Wiley.
- Lovejoy, M.C., Graczyk, P.A., O'Hare, E., & Neuman, G. (2000). Maternal depression and parenting behaviour: A meta-analytic review. *Clinical Psychology Review*, **20** (5), pp. 561-592.
- Luckasson, R., Coulter, D.L., Polloway, E.A., Reiss, S., Schalock, R.L., Snell, M.E., Spitalnik, D.M., & Stark, J.A. (1992). *Mental Retardation: Definition, Classification, and Systems of Supports* (9<sup>th</sup> edition). American Association on Mental Retardation: Washington DC.
- Lustig D.C. (2002). Family coping in families with a child with a disability. *Education and Training in Mental Retardation and Developmental Disabilities*, **37** (1), pp. 14-22.
- Mash, E.J., & Johnston, C. (1983). Parental perceptions of child behaviour problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactives and normal children. *Journal of Consulting and Clinical Psychology*, **51**, pp. 86-99.
- McCubbin, M.A., & Hwang, S.T.T. (1989). Family strengths in the care of handicapped children: Targets for intervention. *Family Relations*, **38**, pp. 436-443.
- McCubbin, H.I., & Patterson, J. (1983). Family stress adaptation to crisis: A double ABCX model of family behaviour. In H. McCubbin, M. Sussman, & J. Patterson (Eds.), *Social Stresses and the Family: advances and developments in family stress theory and research* (pp. 7-37). New York: Haworth Press.
- McCubbin, H., Thompson, A., & McCubbin, M. (1996). *Family assessment: Resiliency, coping and adaptation – inventories for research and practice*. Madison, WI: University of Wisconsin System.
- McKenzie, K., Paxton, D. & Murray, G.C. (2001). An evaluation of community learning disability services for children with a learning disability. *Health Bulletin*, **59** (2), 91-96.
- Meltzer, H., Smyth, M., & Robus, N. (1989). OPCS surveys of disability in Great Britain, report 6, disabled children: services, transport and education. London: HMSO.
- Mink, I., Nihira, K., & Meyers, C. (1983). Taxonomy of family lifestyles: Homes with TMR Children. *American Journal of Mental Deficiency*, **87**, pp. 487-497.
- Minnes, P. (1998). Mental retardation: the impact upon the family. In J.A. Burack, R.M. Hodapp and E. Zigler (Eds.), *Handbook of Mental Retardation and Development* (pp 693-712). New York: Cambridge University Press.

Murray, L., & Cooper, P. (1996). The impact of post-partum depression on child development. *International Review of Psychiatry*, **8**, pp. 55-63.

Neisser, U., Boodoo, G., Bouchard, T. et al (1996). Intelligence knowns and unknowns (report of a task force established by the American Psychological Association). *American Psychologist*, **51**, pp77-101.

Neisser, U., Boodoo, G., & Bouchard, T. (1996). Intelligence knowns and unknowns (report of a task force established by the American Psychological Association). *American Psychologist*, **51**, pp77-101.

Oliver, C. (1995). Self-injurious behaviour in children with learning disabilities: recent advances in assessment and intervention. *Journal of Child Psychology and Psychiatry*, **36**, pp. 909-927.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, **43**, 190-193.

Olson, D.H., McCubbin, H.I., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1983). *Families and What Makes them Work*. Beverley Hills, CA: Sage Publications.

Olsson, M.B., & Hwang, C.P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, **45** (6), pp. 535-543.

Oppenheim, A.N. (1992). *Questionnaire Design, Interviewing and Attitude Measurement*. New Edition. Printer Publishers: London

Parker, G., & Lawton, D. (1991). Further analysis of the 1985 general household survey data on informal care. Report 3: carers and services. York: Social Policy Research Unit Working Paper DHSS 789.

Partington, K.J. (2002). Maternal responses to the diagnosis of learning disabilities in children. *Journal of Learning Disabilities*, **6** (2), 163-173.

Patterson, G.R. (1980). Mothers: The unacknowledged victims. *Monographs of the Society for Research in Child Development*, **45** (5), pp. 1-54

Patterson, J. (1993). The role of family means in adaptation to chronic illness and disability. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.), *Cognitive Coping Research and Developmental Disabilities* (pp. 221-238). Baltimore: Brookes.

Philip, M., & Duckworth, D. (1982). *Children with Disabilities and Their Families: a review of research*. Windsor: NFER-Nelson.

Powell, G.E. (1996). The selection and development of measures. In G. Parry and F.N. Watts (eds). *Behavioural and Mental Health Research. A Handbook of Skill and method* (2<sup>nd</sup> edition), p29-57, Erlbaum: London

Quine, L., & Pahl, J. (1985). Examining the causes of stress in families with severely mentally handicapped children. *Journal of Social Work*, **15**, pp 501-517.

Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transaction model of coping. *Journal of Community and Applied Social Psychology*.

Quine, L., & Wade, K. (1991). Sleep disturbance in children with severe learning difficulties: an examination and an intervention trial. University of Kent at Canterbury: Institute of Social and Applied Psychology and Centre for Health Service Research.

Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, **38**, 344-8.

Rousey, A., Best, S., & Blacher, J. (1992). Mothers and fathers perceptions of stress and coping with children who have severe learning disabilities. *American Journal on Mental Retardation*, **97**, pp. 99-110.

Rutter, M., Graham, P., & Yule, W. (1970). *A Neuropsychiatric Study in Childhood*. London: SIMP/Heinemann.

Ryde-Brandt, B. (1990). Anxiety and defence strategies in mothers of children with different disabilities. *British Journal of Medical Psychology*, **63**, 183-192.

Sameroff, A.J., & Chandler, M.J. (1975). Reproductive risk and the continuum of care taking casualty. In F.D. Horowitz (Ed.), *Review of Child Development Research*. **4**, pp.187-244. Chicago: University of Chicago Press.

Sanders, J.L., & Morgan, S.B. (1997). Family stress and adjustment as perceived by parents of children with autism and Down's syndrome: Implications for intervention. *Child and Family Behaviour Therapy*, **19**, pp. 15-32.

Schild, S. (1971). The family of the retarded child. In R. Koch, & J.C. Dobson (Eds.), *The Mentally Retarded Child and his Family* (pp 431-442). Brunner / Mazel, New York.

Schilling, R.F., Gilchrist, L.D., & Schinke, S.P. (1984). Coping and social support in families of developmentally disabled children. *Family Relations*, **33**, pp. 47-54.

Scott, R.L., Sexton, D., Thompson, B., & Wood, T.A. (1989). Measurement characteristics of the short-form of the questionnaire on resources and stress. *American Journal on Mental Retardation*, **94**, pp. 331-339.

Scott, B., Atkinson, L., Minton, H., & Bowman, T. (1997). Psychological distress of parents of infants with Down's syndrome. *American Journal on Mental Retardation*, **102**, pp. 162-71.

Scottish Executive (2000). *The Same as You? A Review of Services for People with Learning Disabilities*. Scottish Executive: Edinburgh. Scotland: Tactica Solutions.

- Seligman, M., & Darling, R.B. (1989). *Ordinary Families, Special Children*. New York: Guildford Press.
- Shapiro, J. (1983). Family reactions and coping strategies in response to the physically ill or handicapped child. *Social Science and Medicine*, **17**, pp. 913-931.
- Sloper, P., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's syndrome. *Journal of Child Psychology and Psychiatry*, **32**, pp. 655-676.
- Stoneman, Z. (1989). Comparison groups in research on families with mentally retarded members: A methodological and conceptual review. *American Journal of Mental Deficiency*, **86**, pp. 267-274
- Trent, J.W. (1995). *Inventing the Feeble Mind: A history of mental retardation in the United States*. University of California Press: Berkeley, CA.
- Tunali B., Power T.G. (2002). Coping by redefinition: cognitive appraisals in mothers of children with autism and children without autism. *Journal of Autism and Developmental Disabilities*, **32** (1), pp. 25-34.
- Turnbull, A.P., Brotherson, M.J., & Summers, J.A. (1985). The impact of deinstitutionalisation on families: A family systems approach. In R.H. Bruinicks (ed.), *Living and Learning in the Least Restrictive Environment*. Paul H. Brooks: Baltimore.
- Veisson M. (1999). Depression symptoms and emotional states in parents of disabled and non-disabled children. *Social Behaviour and Personality*, **27** (1), 87-98.
- Wallander, J.L., Pitt, L.C., & Mellins, C.A. (1990). Child functional independence and maternal psychosocial stress as risk factors threatening adaptation in mother of physically or sensorially handicapped children. *Journal of Consulting and Clinical Psychology*, **58**, pp. 818-824.
- Warfield, M.E., Krauss, M.W., Hauer-Cram, P., Upshur, C.C., & Shonkoff, J.P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Developmental and Behavioural Paediatrics*, **20** (1), pp. 9-16.
- Webster-Stratton, C. (1991). Strategies for helping families with conduct disordered children. *Journal of Child Psychology and Psychiatry*, **32**, pp. 1047-1062.
- Weiss M.J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, **6** (1), pp. 115-130.
- Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, **51**, 63-70.
- Wikler, L. (1986). Periodic stresses of families of older mentally retarded children: An exploration study. *American Journal of Mental Deficiency*, **99**, pp. 703-706.
- Winzer, M. (1990). *Children with Exceptionalities: A Canadian perspective* (2<sup>nd</sup> Edition). Toronto: Prentice Hall.

Woodroffe, C., Glickman, M., & Barker, M. (1993). *Children, Teenagers and Health: the key data*. Open University Press, Buckingham

Yau, M.K., & Li-Tsang, C.W.P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *The British Journal of Developmental Disabilities*, **45** (1), pp. 38-51.

**Appendices**

## Appendix 1

### Information and Invitation to Research – (Research Subjects)

## **Information and invitation to research**

### **Research Subjects**

I am a final year post-graduate clinical psychology trainee studying at the University of Edinburgh. As part of our final year we must complete a piece of research.

You are being invited to take part in my research project, looking at the difficulties associated with bringing up a child with learning difficulties. Before you decide whether you would like to be a part of this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

### **Background to Research Study**

It has been found that the parents of children with learning difficulties can experience significant stress in relation to the upbringing of their child. These difficulties may be explained in terms of:

- Characteristics of the child, for example; their age, gender, their level of ability and whether they have challenging behaviour or not.
- Characteristics of the mother, for example; whether they are currently experiencing low mood or whether they feel they are supported adequately by friends, relatives and professionals.
- Characteristic of the environment, for example; having a larger family, feeling financially stretched and being a single parent.

All of the above factors can make mothering a child with learning disabilities a very difficult and challenging experience and it is important that we learn more about these factors in order that we as professionals, can support both the mother and her child

### **Aim of Research Study**

The aim of this research project is to ask mothers of children with learning difficulties about the difficulties *they* experience in relation to bringing up their child. This will include asking about demographic details such as where you live, how many children you have etc. It will also involve asking you about your own mood, the stress you experience and the support you get in bringing up your child, to identify whether we as professionals are supporting you sufficiently.

### **Why have I been chosen?**

You have been chosen to take part in this piece of research because you are the mother of a child with learning difficulties, living in the Scottish Borders and known to Dr. Margerison, Consultant Paediatrician.

### **Do I have to take part?**

It is entirely up to you whether you choose to take part in this research study. If you choose to take part, Dr Margerison will inform me and we can meet up after your appointment to complete a short interview. Otherwise we can arrange a more suitable time when I might visit you at home. If you decide to take part, you can withdraw at any time and without giving a reason. **A decision not to take part, or a decision to withdraw at any time, will not affect the standard of care you or your child receive.**



**What will happen to me if I take part?**

This research study will begin in November 2002 and will end in August 2003. If you choose to take part, we can either meet up directly after your appointment with Dr. Margerison, or I will arrange with you to make one visit to your home between November 2002 and April 2003. Your input will involve completing 5 short questionnaires.

Our meeting should last approximately 30 minutes and I will ask you some questions relating to the stress you experience in relation to the upbringing of your child, the support you receive, whether you are currently experiencing low mood and whether your child displays any challenging behaviour. You may refuse to answer any of the questions asked

**Will my taking part in the study be kept confidential?**

All information collected about you and your child during the course of this research project will be kept strictly confidential. No names will be required when completing each of the questionnaires and all further identifiable information will be removed.

**What will happen to the results of the study?**

The results of this study will be written up in the form of a doctoral thesis that will be submitted to the University of Edinburgh in August 2003. A summary of the results obtained will be sent to each subject consenting to take part in the study. No subject will be identified in the thesis.

If you choose to take part in this study I look forward to meeting you, and thank-you for your co-operation. I will be available to discuss any aspects of this study with you after your appointment with Dr. Margerison.

If you choose to take part in this study at a later date, please do not hesitate to contact me on (01896) 668821.

I must stress at this point that participation in the study is voluntary.

Yours Sincerely,

Shona Quin  
Trainee Clinical Psychologist

George Murray  
Consultant Clinical Psychologist

## Appendix 2

### Information and Invitation to Research – (Control Subjects)

## **Information and invitation to research**

### **Control Subjects**

I am a third year post-graduate clinical psychology trainee studying at the University of Edinburgh. As part of our final year we must complete a piece of research.

You are being invited to take part in my research project, looking at the difficulties associated with bringing up a child with learning difficulties. You are being asked to take part as a control subject. This means that the information obtained from yourself will make up a comparison group of mothers of children *without learning difficulties*.

Before you decide whether you would like to be a part of this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

#### **Aim of Research Study**

*The aim of this research project is to ask mothers of children without learning difficulties about the difficulties they experience in relation to bringing up their child to identify any differences apparent between this group and a group of mothers of children with learning difficulties.* We would like to ask a sample of mothers of children without learning difficulties questions about the factors outlined below in order that we might develop a better understanding of the different issues related to bringing up a child with and *without* learning difficulties.

#### **Background to Research Study**

It has been found that the parents of children with learning difficulties can experience significant stress in relation to the upbringing of their child. These difficulties may be explained in terms of:

- Characteristics of the child, for example; their age, gender, their level of ability and whether they have challenging behaviour or not.
- Characteristics of the mother, for example; whether they are currently experiencing low mood or whether they feel they are supported adequately by friends, relatives and professionals.
- Characteristic of the environment, for example; having a larger family, feeling financially stretched and being a single parent.

All of the above factors can make mothering a child with learning disabilities a very difficult and challenging experience and it is important that we learn more about these factors in order that we as professionals, can support both the mother and her child

#### **Why have I been chosen?**

You have been chosen to take part in this piece of research because you are the mother of a child between the ages of 0-16 *without learning difficulties*, living in the Scottish Borders and known to Dr. Margerison, Consultant Paediatrician. If you choose to take part you will be part of what is known as the "control group".

**Do I have to take part?**

It is entirely up to you whether you choose to take part in this research study. If you decide to take part, you can withdraw at any time and without giving a reason. **A decision not to take part, or a decision to withdraw at any time, will not affect the standard of care you or your child receive.**

**What will happen to me if I take part?**

This research study will begin in November 2002 and will end in August 2003. If you choose to take part, we can either meet up directly after your appointment with Dr. Margerison, or I will arrange with you to make one visit to your home between November 2002 and April 2003. Your input will involve completing 4 short questionnaires.

Our meeting should last approximately 30 minutes and I will ask you some questions relating to the stress you experience in relation to the upbringing of your child, the support you receive, whether you are currently experiencing low mood and whether your child displays any challenging behaviour. **You may refuse to answer any of the questions asked**

**Will my taking part in the study be kept confidential?**

All information collected about you and your child during the course of this research project will be kept strictly confidential. No names will be required when completing each of the questionnaires and all further identifiable information will be removed.

**What will happen to the results of the study?**

The results of this study will be written up in the form of a doctoral thesis that will be submitted to the University of Edinburgh in August 2003. A summary of the results obtained will be sent to each subject consenting to take part in the study. No subject will be identified in the thesis.

If you choose to take part in this study I look forward to meeting you, and thank-you for your co-operation. I will be available to discuss any aspects of this study with you after your appointment with Dr. Margerison.

If you choose to take part in this study at a later date, please do not hesitate to contact me on (01896) 668821.

I must stress at this point that participation in the study is voluntary.

Yours Sincerely,

Shona Quin  
Trainee Clinical Psychologist

George Murray  
Consultant Clinical Psychologist

Appendix 3

Consent Form

**CONSENT FORM**

**Title of Project:** AN EXAMINATION OF FACTORS INFLUENCING THE  
EXPERIENCE OF STRESS IN MOTHERS OF CHILDREN  
WITH LEARNING DISABILITIES

**Name of Researcher:** SHONA QUIN  
Trainee Clinical Psychologist

- 1) I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐
- 2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
- 3) I agree to take part in the above study. ☐

\_\_\_\_\_  
Name of Subject                      Date                      Signature

\_\_\_\_\_  
Name of Researcher                      Date                      Signature

If you would like a summary of the results of this project, please give the address you would like the summary to be sent to below:

Address:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Appendix 4

Demographic Questionnaire

### **Demographic Information**

1. Marital Status \_\_\_\_\_
2. Occupation of Main Earner \_\_\_\_\_
3. Number of Children in Household \_\_\_\_\_
4. Does your child have a developmental disability? Yes / No  
(If no, proceed to standardised questionnaires)  
  
If yes, has your child received a diagnosis? Yes / No  
  
Diagnosis \_\_\_\_\_
5. Age of your child with DD: \_\_\_\_\_
6. Gender of your child with DD: Male / Female
7. Does your child have any sensory impairments? Yes / No  
If yes, please specify:  
\_\_\_\_\_
8. Does your child have any physical impairments? Yes / No  
If yes, please specify:  
\_\_\_\_\_  
\_\_\_\_\_
9. Do you feel you receive adequate support? Yes / No  
  
If not, what additional support do you require?  
  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## Appendix 5

### Challenging Behaviour Questionnaire

**Challenging Behaviour**

1. Does your child display challenging behaviour or behaviour that you find difficult to deal with?

YES / NO

Please indicate in the table below, which behaviours your child displays

| BEHAVIOUR  | Present in my child |
|--|---------------------|
| Violence and Aggression towards others:<br>(e.g. hitting, biting, pulling hair etc.)       |                     |
| Self-Injurious Behaviour<br>(e.g. head banging, eye-poking, hand-biting etc.)              |                     |
| Destructive Behaviour<br>(e.g. breaking windows, tearing clothes, throwing furniture etc.) |                     |
| Disruptive Anti-social Behaviour<br>(e.g. screaming, running away, stripping etc.)         |                     |
| Stereotyped Behaviour<br>(e.g. body rocking, finger flicking, pacing etc.)                 |                     |
| Overly Passive Behaviour<br>(e.g. withdrawal, lack of engagement etc.)                     |                     |
| Other:<br>(Please specify)   |                     |

Appendix 6

Beck Depression Inventory – II

|   |   |
|---|---|
| <p><b>1. General</b></p> <p>1. I feel sad most of the time.</p> <p>2. I feel sad most of the time.</p> <p>3. I feel sad most of the time.</p> <p>4. I feel sad most of the time.</p>      | <p><b>5. General</b></p> <p>5. I feel sad most of the time.</p> <p>6. I feel sad most of the time.</p> <p>7. I feel sad most of the time.</p> <p>8. I feel sad most of the time.</p>      |
| <p><b>2. Thoughts</b></p> <p>9. I feel sad most of the time.</p> <p>10. I feel sad most of the time.</p> <p>11. I feel sad most of the time.</p> <p>12. I feel sad most of the time.</p>  | <p><b>9. General</b></p> <p>9. I feel sad most of the time.</p> <p>10. I feel sad most of the time.</p> <p>11. I feel sad most of the time.</p> <p>12. I feel sad most of the time.</p>   |
| <p><b>3. Feelings</b></p> <p>13. I feel sad most of the time.</p> <p>14. I feel sad most of the time.</p> <p>15. I feel sad most of the time.</p> <p>16. I feel sad most of the time.</p> | <p><b>13. General</b></p> <p>13. I feel sad most of the time.</p> <p>14. I feel sad most of the time.</p> <p>15. I feel sad most of the time.</p> <p>16. I feel sad most of the time.</p> |
| <p><b>4. Thoughts</b></p> <p>17. I feel sad most of the time.</p> <p>18. I feel sad most of the time.</p> <p>19. I feel sad most of the time.</p> <p>20. I feel sad most of the time.</p> | <p><b>17. General</b></p> <p>17. I feel sad most of the time.</p> <p>18. I feel sad most of the time.</p> <p>19. I feel sad most of the time.</p> <p>20. I feel sad most of the time.</p> |
| <p><b>5. Feelings</b></p> <p>21. I feel sad most of the time.</p> <p>22. I feel sad most of the time.</p> <p>23. I feel sad most of the time.</p> <p>24. I feel sad most of the time.</p> | <p><b>21. General</b></p> <p>21. I feel sad most of the time.</p> <p>22. I feel sad most of the time.</p> <p>23. I feel sad most of the time.</p> <p>24. I feel sad most of the time.</p> |
| <p><b>6. Thoughts</b></p> <p>25. I feel sad most of the time.</p> <p>26. I feel sad most of the time.</p> <p>27. I feel sad most of the time.</p> <p>28. I feel sad most of the time.</p> | <p><b>25. General</b></p> <p>25. I feel sad most of the time.</p> <p>26. I feel sad most of the time.</p> <p>27. I feel sad most of the time.</p> <p>28. I feel sad most of the time.</p> |
| <p><b>7. Feelings</b></p> <p>29. I feel sad most of the time.</p> <p>30. I feel sad most of the time.</p> <p>31. I feel sad most of the time.</p> <p>32. I feel sad most of the time.</p> | <p><b>29. General</b></p> <p>29. I feel sad most of the time.</p> <p>30. I feel sad most of the time.</p> <p>31. I feel sad most of the time.</p> <p>32. I feel sad most of the time.</p> |
| <p><b>8. Thoughts</b></p> <p>33. I feel sad most of the time.</p> <p>34. I feel sad most of the time.</p> <p>35. I feel sad most of the time.</p> <p>36. I feel sad most of the time.</p> | <p><b>33. General</b></p> <p>33. I feel sad most of the time.</p> <p>34. I feel sad most of the time.</p> <p>35. I feel sad most of the time.</p> <p>36. I feel sad most of the time.</p> |

Name: \_\_\_\_\_ Marital Status: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Occupation: \_\_\_\_\_ Education: \_\_\_\_\_

**Instructions:** This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

**1. Sadness**

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

**2. Pessimism**

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

**3. Past Failure**

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

**4. Loss of Pleasure**

- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

**5. Guilty Feelings**

- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

**6. Punishment Feelings**

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

**7. Self-Dislike**

- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

**8. Self-Criticalness**

- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

**9. Suicidal Thoughts or Wishes**

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

**10. Crying**

- 0 I don't cry anymore than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

Subtotal Page 1

**Continued on Back**

**11. Agitation**

- 0 I am no more restless or wound up than usual.
- 1 I feel more restless or wound up than usual.
- 2 I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

**12. Loss of Interest**

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- 2 I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

**13. Indecisiveness**

- 0 I make decisions about as well as ever.
- 1 I find it more difficult to make decisions than usual.
- 2 I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

**14. Worthlessness**

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compared to other people.
- 3 I feel utterly worthless.

**15. Loss of Energy**

- 0 I have as much energy as ever.
- 1 I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- 3 I don't have enough energy to do anything.

**16. Changes in Sleeping Pattern**

- 0 I have not experienced any change in my sleeping pattern.
- 1a I sleep somewhat more than usual.
- 1b I sleep somewhat less than usual.
- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.
- 3a I sleep most of the day.
- 3b I wake up 1-2 hours early and can't get back to sleep.

**17. Irritability**

- 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

**18. Changes in Appetite**

- 0 I have not experienced any change in my appetite.
- 1a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.
- 2a My appetite is much less than before.
- 2b My appetite is much greater than usual.
- 3a I have no appetite at all.
- 3b I crave food all the time.

**19. Concentration Difficulty**

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

**20. Tiredness or Fatigue**

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

**21. Loss of Interest in Sex**

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

## Appendix 7

### Questionnaire on Resources and Stress – Revised Edition



Read each item and think about your feelings about it and your family. There are many things which influence your feelings and opinions, and you should think about these things when you answer the questions. You may not always agree with the statements, but you should answer the questions as you feel about them. There are no right or wrong answers. The questions are about your feelings and opinions, and you should answer them as you feel about them. There are no right or wrong answers. The questions are about your feelings and opinions, and you should answer them as you feel about them.

\_\_\_\_\_ I am often worried about my health and the health of my family. ☐ T ☐ F

\_\_\_\_\_ One thing worries me about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ My family worries me about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

\_\_\_\_\_ I worry about my health because of \_\_\_\_\_ ☐ T ☐ F

# A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)



This questionnaire asks about your feelings about a child in your family. There are many blanks in the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide whether to circle True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please remember to answer all of the questions.

1. \_\_\_\_\_ doesn't communicate with others of his/her age group

|   |   |
|---|---|
| T | F |
|---|---|

2. Other family members do without things because of \_\_\_\_\_

|   |   |
|---|---|
| T | F |
|---|---|

3. Our family agrees on important matters

|   |   |
|---|---|
| T | F |
|---|---|

4. I worry what will happen to \_\_\_\_\_ when I can no longer take care of him/her

|   |   |
|---|---|
| T | F |
|---|---|

5. Constant demands to care for \_\_\_\_\_ limit the growth and development of someone else in our family

|   |   |
|---|---|
| T | F |
|---|---|

6. \_\_\_\_\_ is limited in the kind of work he/she can do to make a living

|   |   |
|---|---|
| T | F |
|---|---|

7. I have accepted that \_\_\_\_\_ might have to live out his/her life in a special setting (e.g. institution or group home)

|   |   |
|---|---|
| T | F |
|---|---|

8. \_\_\_\_\_ can feed himself/herself

|   |   |
|---|---|
| T | F |
|---|---|

9. I have given up things I really wanted to care for \_\_\_\_\_

|   |   |
|---|---|
| T | F |
|---|---|

10. \_\_\_\_\_ is able to fit into the family social group

|   |   |
|---|---|
| T | F |
|---|---|

11. Sometimes I avoid taking \_\_\_\_\_ out in public

|   |   |
|---|---|
| T | F |
|---|---|

12. In the future, our family's social life will suffer because of increased responsibilities and financial stress

|   |   |
|---|---|
| T | F |
|---|---|

13. It bothers me that \_\_\_\_\_ will always be this way

|   |   |
|---|---|
| T | F |
|---|---|

14. I feel tense whenever I take \_\_\_\_\_ out in public

|   |   |
|---|---|
| T | F |
|---|---|

15. I can go to visit friends whenever I want

|   |   |
|---|---|
| T | F |
|---|---|

16. Taking \_\_\_\_\_ on holiday spoils pleasure for the whole family

|   |   |
|---|---|
| T | F |
|---|---|

17. \_\_\_\_\_ knows his/her own address

|   |   |
|---|---|
| T | F |
|---|---|

18. The family does as many things together now as we ever did

|   |   |
|---|---|
| T | F |
|---|---|





- \_\_\_\_\_ is aware of who he/she is ☐ T ☐ F
- I get upset with the way my life is going ☐ T ☐ F
- Sometimes I feel very embarrassed because of \_\_\_\_\_ ☐ T ☐ F
- \_\_\_\_\_ doesn't do as much as he/she should be able to do. ☐ T ☐ F
- It is difficult to communicate with \_\_\_\_\_ because he/she has difficulty understanding what is being said to him/her ☐ T ☐ F
- There are many places we can enjoy ourselves as a family when \_\_\_\_\_ comes along ☐ T ☐ F
- \_\_\_\_\_ is over-protected ☐ T ☐ F
- \_\_\_\_\_ is able to take part in games or sports ☐ T ☐ F
- \_\_\_\_\_ has too much time on his/her hands ☐ T ☐ F
- I am disappointed that \_\_\_\_\_ does not lead a normal life ☐ T ☐ F
- Time drags for \_\_\_\_\_, especially free time ☐ T ☐ F
- \_\_\_\_\_ can't pay attention for very long ☐ T ☐ F
- It is easy for me to relax ☐ T ☐ F
- I worry what will happen to \_\_\_\_\_ when he/she gets older ☐ T ☐ F
- I get almost too tired to enjoy myself ☐ T ☐ F
- One of the things I appreciate about \_\_\_\_\_ is his/her confidence ☐ T ☐ F
- There is a lot of anger and resentment in our family ☐ T ☐ F
- \_\_\_\_\_ is able to go to the bathroom alone ☐ T ☐ F
- \_\_\_\_\_ can't remember what he/she says from one moment to the next ☐ T ☐ F
- \_\_\_\_\_ can ride on a bus ☐ T ☐ F
- It is easy to communicate with \_\_\_\_\_ ☐ T ☐ F
- Constant demands to care for \_\_\_\_\_ limit my growth and development ☐ T ☐ F





41. \_\_\_\_\_ accepts himself/herself as a person

T

F

42. I feel sad when I think of \_\_\_\_\_

T

F

43. I often worry what will happen to \_\_\_\_\_ when I can no longer take care of him/her

T

F

44. People can't understand what \_\_\_\_\_ tries to say

T

F

45. Caring for \_\_\_\_\_ puts a strain on me

T

F

46. Members of our family get to do the same kinds of things that other families do

T

F

47. \_\_\_\_\_ will always be a problem to us

T

F

48. \_\_\_\_\_ is able to express his/her feelings to others

T

F

49. \_\_\_\_\_ has to use a bedpan or a nappy

T

F

50. I rarely feel blue

T

F

51. I am worried much of the time

T

F

52. \_\_\_\_\_ can walk without help

T

F



© Friedrich, 1983. *Questionnaire on Resources and Stress* by William Friedrich from Friedrich, W. N., Greenberg M. T. and Crnic, K., 'A short-form of the Questionnaire on Resources and Stress', *American Journal of Mental Deficiency*, Vol. 88, 41-48, 1983. Reproduced by kind permission of the author and the publishers, the American Association on Mental Retardation, Washington, DC.

This measure is part of *The Child Psychology Portfolio* edited by Irene Sclare. Once the invoice has been paid it may be photocopied for use **within the purchasing institution only**. Published by The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 405905.

Appendix 8

Family Support Scale

FAMILY SUPPORT SCALE (FSS)  
DRAST, JENNIFER AND TAYLOR, J.



The Family Support Scale (FSS) is a self-report measure of family support. It consists of 10 items, each rated on a 5-point scale from 1 (Not at all) to 5 (Very much). The total score ranges from 10 to 50. The FSS is a measure of family support, not family conflict. It is a measure of family support, not family conflict. It is a measure of family support, not family conflict.

- 1. I feel that my family is supportive of me.
- 2. I feel that my family is understanding of me.
- 3. I feel that my family is helpful to me.
- 4. I feel that my family is caring for me.
- 5. I feel that my family is interested in me.
- 6. I feel that my family is proud of me.
- 7. I feel that my family is respectful of me.
- 8. I feel that my family is loving to me.
- 9. I feel that my family is supportive of my goals.
- 10. I feel that my family is supportive of my needs.



|    |   |   |   |   |   |
|----|---|---|---|---|---|
| 10 | 1 | 2 | 3 | 4 | 5 |
| 15 | 1 | 2 | 3 | 4 | 5 |
| 20 | 1 | 2 | 3 | 4 | 5 |
| 25 | 1 | 2 | 3 | 4 | 5 |
| 30 | 1 | 2 | 3 | 4 | 5 |
| 35 | 1 | 2 | 3 | 4 | 5 |
| 40 | 1 | 2 | 3 | 4 | 5 |
| 45 | 1 | 2 | 3 | 4 | 5 |
| 50 | 1 | 2 | 3 | 4 | 5 |

Copyright © 1999 by the Department of Health and Human Services. All rights reserved. This document is a copyrighted work of the Department of Health and Human Services. It is not to be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or by any information storage and retrieval system, without prior written permission from the Department of Health and Human Services.

# FAMILY SUPPORT SCALE (FSS)



(ADAPTED FROM DUNST, JENKINS AND TRIVETTE)

listed below are sources of support that are often helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to *your family*. Please *circle* the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (not available) response.

|  | Not available | Not helpful at all | Sometimes helpful | Generally helpful | Very helpful | Extremely helpful |
|--|---------------|--------------------|-------------------|-------------------|--------------|-------------------|
| 1. My parents  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 2. My partner/spouse's parents   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 3. My relatives/kin  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 4. My partner/spouse's relatives/kin   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 5. Partner/spouse  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 6. My friends  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 7. My partner/spouse's friends   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 8. My own children   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 9. Other parents   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 10. Co-workers   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 11. Parent groups  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 12. Social groups/clubs  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 13. Place of worship/religious organization                                    | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 14. My family or child's doctor  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 15. Professional helpers (social workers, therapists, teachers, etc.)          | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 16. Professional agencies (public health, social services, mental health, etc) | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 17. School/day-care centre   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
| 18. Early intervention programme   | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
|  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |
|  | NA            | 1                  | 2                 | 3                 | 4            | 5                 |

© 1993, Dunst, Trivette and Hamby. *Family Support Scale* by Carl J. Dunst, Carol M. Trivette and Deborah W. Hamby from Dunst, C. J., Trivette, C. M. and Deal, A. G. (Eds) (1994). *Supporting and Strengthening Families, Volume 1: Methods, Strategies and Practices*. Reproduced by kind permission of the authors and publishers, Brookline Books, Cambridge, MA.

This measure is part of *The Child Psychology Portfolio* edited by Irene Sclare. Once the invoice has been paid, it may be photocopied for use **within the purchasing institution only**. Published by The NFER-Nelson Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DE, UK. Code 4050054



## Appendix 9

### Scoring Criteria for Non-standardised Questionnaires

## Appendix 9

### Scoring criteria for Non-standardised Questionnaires

#### **Demographic Questionnaire**

##### 1) Marital Status

Single =1  
Married =2

##### 2) Occupation of Main Earner

Unemployed =1  
Manual Worker =2  
Professional =3

##### 6) Diagnosis

Global Learning Disability =0  
ADHD =1  
Down's syndrome =2  
Specific Learning Difficulty =3  
Autism =4  
Noonan's syndrome =5  
Cerebral Palsy =6

##### 13) Support Required

Respite =1  
Child related professional =2  
Personal professional =3  
Information =4  
Support groups =5

Appendix 10

Hypothesis 1 – Descriptive Data

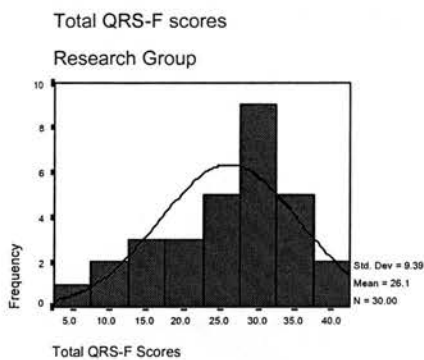
Appendix 10

Hypothesis 1 – Descriptive Data

Graphs H1.1 and H1.2 illustrate the distribution of total QRS-F scores for both groups.

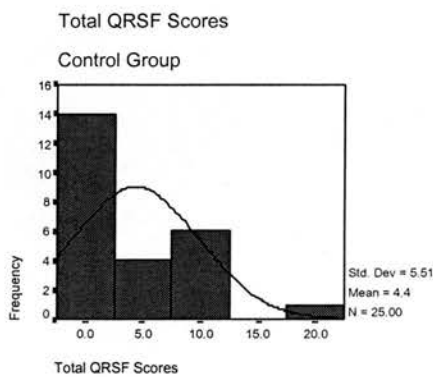
Graph H1.1

Distribution of QRS-F scores of Research Group



Graph H1.2

Distribution of QRS-F scores of Control Group

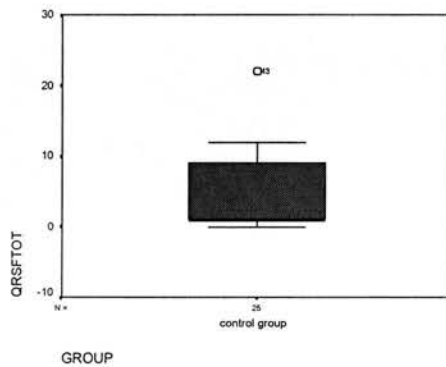


QRS-F scores for the research group are normally distributed (skewness =  $-.414$ , std error of skewness =  $.427$ ). However, QRS-F scores for the control group are highly positively skewed

(skewness = 1.617, std error of skewness = .464). From the distribution of QRS-F scores for the control group an outlier can be identified. This is further illustrated in boxplot H1.1 below:

### Boxplot H1.1

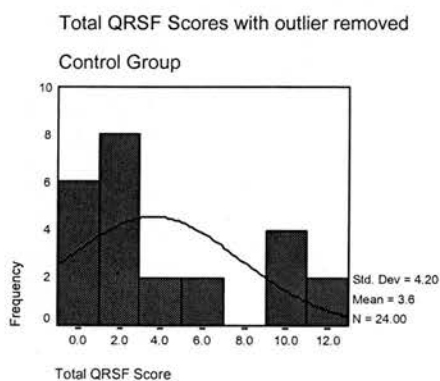
#### Illustration of outlier present in control group data



This case was removed from the analysis thus reducing the skewness of the data (skewness = .898, std error of skewness = .472). Having removed this outlier, the QRS-F scores for the control group became normally distributed. See graph H1.3 below.

### Graph H1.3

#### Distribution of QRS-F scores of Control Group with Outlier Removed





Appendix 11

Hypothesis 3 – Descriptive Data

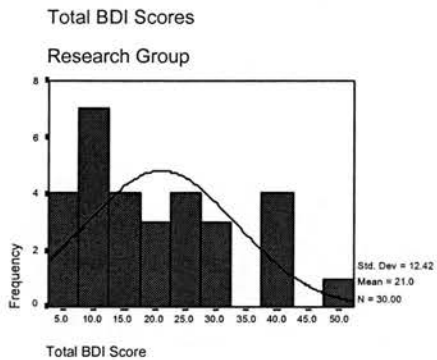
## Appendix 11

### Hypothesis 3 – Descriptive Data

Graphs H3.1 and H3.2 plot the frequency of total scores on the BDI for both groups

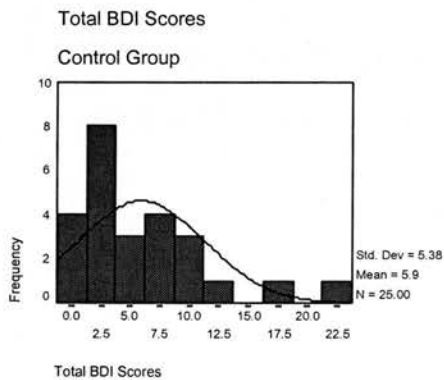
#### Graph H3.1

##### The Frequency of Total BDI Scores (Research Group)



#### Graph H3.2

##### The Frequency of Total BDI Scores (Control Group)

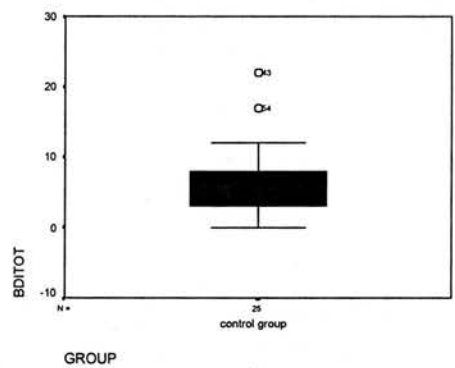


BDI scores for the research group fall within a pattern of normal distribution (skewness = .690, std error of skewness = .427). However, control group BDI scores are not normally distributed

(skewness = 1.446, std error of skewness = .464). From the distribution of control group data, however, there are two outliers that appeared to be influencing the skewed nature of the data. These can be identified further in boxplot H3.1 below

Boxplot H3.1

Illustration of Outliers present in Control Group Data



Once these two outliers were removed, the control group data became normally distributed.

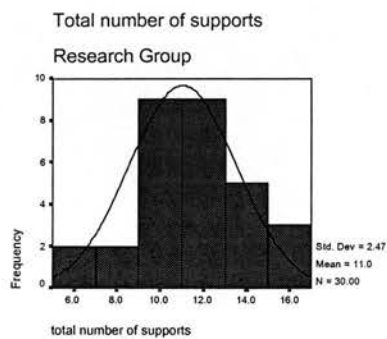
## Appendix 12

### Hypothesis 4 – Distribution of Number of Supports

Appendix 12

Distribution of Number of Supports

Distribution of Total of Number of Supports (Research Group)



Distribution of Total Number of Supports (Control group)

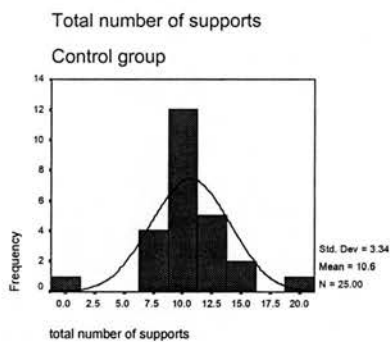
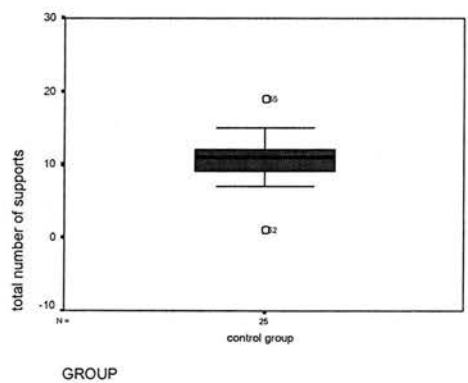


Illustration of Outliers Present in Control Group Data



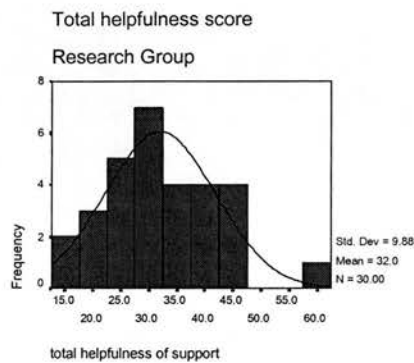
Appendix 13

Distribution of Helpfulness of Supports

Appendix 13

Distribution of Helpfulness of Supports

Distribution of Total Helpfulness of Supports (Research Group)



Distribution of Total Helpfulness of Supports (Control Group)

